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ABSTRACT

The proceedings of the Second Annual Meeting and Conference of the National Society for Autistic Children begin with three brief statements regarding the Joint Commission on Mental Health of Children. Following are the keynote address by Edwin W. Martin concerning the rhetoric and reality of the Federal response to the educational needs of handicapped children, and other addresses on the strengths and weaknesses of operant conditioning techniques for the treatment of autism (O. Ivar Lovaas), autism as a deficiency in context-dependent processes (Karl H. Pribram), the autistic child as teacher and learner (Frank M. Hewett), and the Institute for Child Behavior research study of high dosage vitamins as a method of treating severely mentally ill children (Bernard Rimland). Workshop presentations and parent panels included cover such topics as the Edison Responsive Environment (or talking typewriter) used with autistic children; problems of management, training, and education as discussed by parents of autistic children of various ages; federal resources; how to work with state legislatures; a public school program for autistic children; and the Irish Society for Autistic Children. A list of eight recommended films is included. (KW)

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# "Research and Education:

# Top Priorities for Mentally Ill Children"

## 2nd Annual Meeting and Conference
## of the
## National Society for Autistic Children

June 24-27, 1970
San Francisco

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# CONFERENCE AND ANNUAL MEETING
of the
# NATIONAL SOCIETY FOR AUTISTIC CHILDREN

San Francisco

June 24-27, 1970

"Research and Education: Top Priorities for Mentally Ill Children"

## PROCEEDINGS

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# Foreword

This was a rather remarkable Conference for several reasons. First, it clearly demonstrated the ability of a parents' group to plan, organize, and develop a program addressed to the needs and interests of both providers and consumers of services. It also established a climate for the interchange of vital information between those who live with the problem of autism and those who work with it. Further, the program format uniquely illustrated that participation of both professionals and consumers can provide experiences and insights so necessary to the development of a body of knowledge.

It was our feeling that dissemination of these proceedings to parents of autistic children would, at the very least, offer a source of hope for the future. Similarly, it was our feeling that distribution of this Conference report to interested professionals would provide an additional source of inspiration for renewed dedication to research, training, and service in autism.

Herbert L. Rooney, Chief
Citizen Participation Branch
Office of Program Liaison
National Institute of Mental Health

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# INTRODUCTION

Ruth Christ Sullivan
President, National Society for Autistic Children
July 1968 to June 1970

"What will you do for an encore?" had been the refrain in July 1969, in Washington, D.C. after our First Annual Conference. It expressed the wonder of it all--that not only was the new, struggling, and widely scattered band of parents and dedicated professionals viable, but that it was well and surprisingly sturdy. Our First Annual Conference (Theme: "Better Everything for Mentally Ill Children") had been successful beyond our fondest dreams.

But as the worrisome refrain echoed, we wondered if we could plan the 1970 Conference so that it too would electrify, mobilize, innervate, consolidate. Dr. Bernard Rimland, founder of NSAC, had said, "For most people on earth, July 1969, will be the month man walked on the moon, but for those of us lucky enough to be at the NSAC meetings in Washington, it will be remembered as the month of the First Annual Convention of our Society." Dr. Carl Fenichel, Director of the famous League School in Brooklyn, the keynote speaker, had said,

> As a veteran of almost two decades of meetings all over America in behalf of mentally ill children, I found this one to be by far one of the most productive, exciting, and memorable I have ever attended. I was deeply moved and impressed by the people as well as the program. The dedication, enthusiasm and total involvement and interaction of the parents and professionals were rare and heartening experiences that I would love to see replicated elsewhere....

Well, it was replicated--in San Francisco in June 1970. Again, top-level people accepted our invitation, in spite of knowing we might not be able to pay even their expenses. Again, parents and professionals came from all parts of this country and Canada. Several came from abroad. The phenomenon was repeatable. The level of communication seemed to be at its peak--parents with professionals, parents with parents, professionals with professionals. Dr. Eric Schopler summed it up after he got home:

> I have attended both of the first two annual meetings and continue to be impressed with the interest, vitality and quality of the parents' participation. They seem to talk to each other more and make better use of available information than do most participants of professional meetings. Maybe it's the groups' combined energy and talent, and living in more of a pressure cooker than their professional counterparts that makes for that vitality. Let me take this emotional climate one step further and consider the intellectual output of this group. If you rack up the contribution of parents like Rimland, Wing, Park, Kysar, May, Eberhardy, Junker against the professional contributions to the literature on autism, these parents may easily have made a more lasting contribution than has the professional group.

...I for one suspect that this group stands for attitudes and policies in the forefront of how the field is and probably should be moving.

As Clara Park, our Newsletter editor, wrote in the Special Issue reporting on the 1970 Conference, "No collection of printed words will bring you the Conference: the corridor contacts, the exchanges of information on books, films, schools, methods, the discussions after workshops, the personal reality of the speakers--were too rich a mix to confine in black and white." Throughout the meeting we encouraged little meetings--a mother of two autistic children asked to meet with other parents with the same problem; a mother of a pretty teenage autistic daughter wanted to meet with parents like her. Parents of autistic-deaf or autistic-blind children met each other. Speech therapists, social workers, psychologists, biochemists, were seen in small huddles in meeting room corners, in the halls, at meals. It is an exciting thought that if all the collective knowledge at that meeting could be synthesized, there might possibly have been, there at the Sheraton-Palace, the answer to what causes mental illness in children! We like to think that perhaps the piecing together of that answer was somehow hastened by our Conference.

One of the most important offshoots of this and our 1969 Conference was the participation of parents and professionals on an equal basis. For many parents this was the first time of meeting professionals without being "the patient" or "the family". One mother wrote later, "I feel the entire NSAC meeting was a tremendous event. It was very encouraging to me to find so many professionals on our side!"

That there are "sides" is, of course, well known. Most parents have met the "what have you done to this child?" professional. Parents of mentally ill children learn, perforce, to be wary of professionals until they establish which "side" they're on. If there were many of the psychogenesis variety at the San Francisco meeting, they made a low silhouette. Meeting large numbers of truly interested, warm professional people who also were searching for information and help was for many parents a unique experience.

It was unique for many professionals too. One psychologist remarked that she came reluctantly, afraid that at such a "mixed" meeting she would be overwhelmed by parents' self-pity and complaints. She was happily surprised to find instead a well-informed, articulate, and relatively objective group of parents, chairing meetings and workshops and participating in discussions with expertise and aplomb. A number of professionals pointed out that this Conference was conducted better than most professional meetings they had attended. They saw the parents in a different role. If this Conference did no more than nourish the mutual respect of parents and professionals, it would have been worth the effort.

One of the most important goals of NSAC is disseminating information about mentally ill children. The Annual Conference is one method of doing this, and it is heartening that even before our first Conference we were already getting calls for presentation of papers. In the few months before our 1970 meeting we got two dozen such requests. Perhaps our future Conferences can stimulate even more interest.

On an international level, our Conference attracted the attention of the more than 16 parent-oriented Societies throughout the world. We had personally invited each Society president known to us to our San Francisco meeting. We were delighted that Dr. Catherine Crawley of Dublin, founder and President of the Irish Society for Autistic Children, was able to come. Denmark sent two representatives, Mr. and Mrs. Hansen of The Sofieskolen in Copenhagen. The peculiar problems faced by parents of mentally ill children are, it seems, essentially the same, whether it be Japan, Australia, South Africa, England, or the United States. Among the many messages of good wishes received from abroad for our Conference was one from Drs. Francoise and Alfred Brauner of Paris:

> **We will not be with you in San Francisco this year because we cannot leave our 80 children, and the road is long and expensive for three days...(but) we watchfully follow the growth of your Society. We have followed your efforts to combat explanations that are too simplistic in the matter of etiology of autism. Not only do they do injustice to families already under trial by the presence of an autistic child, but they slow scientific research which would look for organic causes....**

Like us, Societies in other countries place education and research among their top priorities.

There were highlights of the meeting that were not on the program and are not found in these Proceedings, such as

-- the joy of meeting other human beings to whom, in Harriet Mandelbaum's words, "one need not explain the meaning of autism, and who, in addition, do not have to be persuaded of the very existence of mentally ill children."

-- the amusing skit poking not-so-gentle fun at psychiatrists who blame mothers, written by TV playwright, parent-member Robert Crean of Larchmont, New York, and beautifully performed by members of the San Francisco Actors Conservatory Theatre under the direction of Arthur Stubbs.

-- the special message from Dr. Bertram S. Brown, the newly appointed Director of NIMH, eloquently delivered by Herbert L. Rooney, Chief of the Citizen Participation Branch of NIMH, in which Dr. Brown specifies autistic children as a target group for assistance during his administration.

-- the presence of Mr. David J. O'Connell, producer of The Marcus Welby, M.D. TV series, who, with his wife, made a special trip to San Francisco to receive NSAC's first public service award for "The Foal", about an autistic child.

-- the opportunity to see at first-hand the legendary "talking typewriter" and meet personally with Mr. Norman Kreisman, Vice President of The Responsive Environment Corporation of Washington, D.C.

-- the camaraderie of the conference-goers and seeing with our own eyes the refutation of the mindlessly repeated labels, "cold", "uncomfortable with people", "refrigerator parents"!

-- the poignant, unspeakably touching and unfaltering presentation by William J. Donovan, 21, of "My Experiences as an Autistic Child" and the soft-hearted, hard-headed questions tenderly submitted by members of the audience.

And many more --

Since NSAC is an all-volunteer organization, this Conference was the result of a tremendous amount of time-consuming, loving effort on the part of many. We were fortunate to have as our Conference Chairman, John J. (Jack) Kyne of San Jose, California. Like Jane Salzano of Rockville, Maryland, whose unusual organizational ability guided us through our 1969 Conference in Washington, Jack Kyne took over in San Francisco. He and his wife,Jan, Judy Etheridge, also of San Jose, and volunteers and recruits too numerous to mention, worked out the complicated logistics which usually go unnoticed unless something goes wrong.

Special mention should go to Dana Neimark of Silver Spring, Maryland, and Dorothy Miller, Pleasant Hill, California, who set up an impressive literature display, with much free material, and to Frances Eberhardy of Madison, Wisconsin, who was responsible for the film presentations. Our gratitude also goes to Jefferson Grigsby of Corte Madera, California and Mildred Gluth, Anaheim, California for handling publicity, meaning, among other things, personally delivering news releases to the local media and the wire services, sometimes even at midnight. We offer a special thanks to new NSAC friends, Jeannette and Scott Hunsinger of San Francisco (Vice President of the Bank of America) who helped immeasurably during our Conference in their beautiful city.

On a personal note, I'd like to say thanks to the very special group of people who comprise my family. Without their cooperation and active help, there would have been much less time available for planning this Conference. (Researchers please note: In spite of "severe maternal deprivation" during the two years of my presidency, there is still only one of our seven children, ages 5-16, who is autistic.)

These Proceedings, under the editorship of Clara Park, will stand as a monument to the determination of parents to gain for their mentally ill children something considerably better than the back ward of a state institution. For our children we want better everything, the most urgent of which are research and education.

Where NSAC parents are, things begin to happen.

**Mrs. Sullivan, a registered nurse before the birth of her children, was a Founding Member of NSAC and President of the Capitol District Chapter, which covers the New York State House. Mrs. Sullivan had plenty of opportunity there to practise the legislative expertise she gained in the League of Women Voters, before she moved on to the national level. She is married to William Sullivan, Professor of English at Marshall University, Huntington, West Virginia, who edits the NSAC Bibliography of books and articles on autism.**

## OPENING SESSION

## NSAC POSITION ON THE REPORT OF THE JOINT COMMISSION ON THE MENTAL HEALTH OF CHILDREN

Ruth Christ Sullivan

It is said that one of the most important pieces of legislation for mentally ill children ever passed by the United States Congress was the creation in 1965 of the Joint Commission on Mental Health of Children. Under the direction of Dr. Reginald Lourie, a child psychiatrist, and with one and a half million dollars, the Commission began its work. In the summer of 1969, it made its recommendations to the Congress. The Report of the Joint Commission is of deep concern to this Society, since we are the only national organization which lives, moves and has its being for the very same goals for which the Joint Commission was established. It is significant, however, that no one from our organization, nor any person officially representing parents served on the Joint Commission or its Task Forces. It should be of no surprise, then, that in the view of those of us who live with the problem twenty-four hours a day, the Joint Commission does not reflect the urgencies as we see them.

In February 1969, the Joint Commission held a meeting with all of its affiliate organizations, at which time NSAC made a strong protest*against the Joint Commission theme that if children had happier homes they would not be mentally ill. We pointed out that up to that time there had been no report from the basic sciences, even though much new evidence supported the view that mental illness is caused by some biochemical error. We made a number of recommendations of our own, and asked that parents be consulted before the Joint Commission made its final recommendations. We were not.

After the Joint Commission's Report was made early last summer, it was clear that the Child Advocacy System was considered to have top priority. NSAC then wrote another position paper*from which we excerpt the following:

There is a vigorous and strong support from not only our NSAC Board, but from the membership at large, especially parents (the consumers), for Research and Education as top

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*Full texts available from NSAC

priorities, not a Child Advocacy system. That this is the main recommendation of the Joint Commission is a deep disappointment. The Child Advocacy system proposal is based on the theory that mental illness and emotional disturbances are caused by psychosocial environment. If society offers a reasonably happy, confortable and good life to a child, the theory goes, he will not become emotionally disturbed or mentally ill. They say mental illness will not be cured until society is cured. To this end, the Joint Commission proposes no less than restructuring society.

The system of Advocacy as proposed by the Joint Commission is for all children, with no emphasis on the child for whose welfare they were commissioned! We would like to point out that the two national "consumer" organizations---the only ones which have active participation by parents of mentally ill children---(National Association for Mental Health and NSAC) are the only two who have seriously and repeatedly questioned the wisdom of an advocacy system as top priority among the Joint Commission recommendations. The principal support for an advocacy system comes from two "seller" groups--the American Psychiatric Association and the American Psychoanalytic Association. Though we endorse the need for advocacy, at all levels of government, we feel that SERVICE is the need which cries out the loudest. The Joint Commission recommendations state that the advocates shall not provide direct services. Their function is to guide the child and his family to appropriate services. For mentally ill children, there are seldom any services, appropriate or otherwise, to be guided to. Since the advocates are not to provide direct services, this leaves mentally ill children almost exactly where they are now.

The Neighborhood Office of Child Advocacy is granted powers to purchase services and facilitate the creation of new services.** Since education is at this time the most important form of service for mentally ill children, will the NOCA be authorized and willing to make grants to school systems which will and surely should be the most important producer of services for children? Does this mean NOCA will be the granting agency for special education funds? If so, how will this affect such programs as ESEA?

** Working Draft prepared for the JCMHC by Arthur Bolton Associates, March, 1970.

If one did not know the sponsor of the Child Advocacy recommendation, one would be hard put to find any clues that this proposal was made by a commission whose sole duty it was to find answers to the problem of mental illness in children.

One further point: There is little in the proposed Child Advocacy System that could not fit into the already existing Community Mental Health Centers. Though few existing Centers now give adequate services to children, there is no reason they cannot add programs for children. It would seem much more feasible, efficient and economical to place mental health services for children in the newly emerged mental health centers than to create yet another even bigger, more costly (and in our opinion, less effective) bureaucracy.

Time is urgent for thousands of mentally ill children who cannot wait ten years for a new system. We propose instead expanding already existing facilities (especially schools and mental health centers) which could, with much less than ten billion dollars a year, for ten years--an estimate for implementing the Joint Commission's recommendations--care for today's children now. This nation has money, know-how, good will. There are eager workers. Let us make sure that the forces we set in motion are useful, precise and powerful so that we do not run the risk of dissipating this historical momentum. Our children wait!

Our new "Statement of Principles" sets as top priorities research and education.

There should be immediate and well funded support by the federal government for basic and applied research programs to discover the causes, cure, and prevention of mental illness in children. There are presently a number of researchers working in the field of biochemistry, for instance, whose important work is curtailed or in some instances cancelled for lack of funds. There are pitifully few federally funded projects working on physical causes for mental illness in children. Research funded in the past has been for such projects as methods of treatment (before the cause is known), methods of identification, studies of parental attitudes, group therapy, etc.. If polio had been approached in this way, it is not likely there would even yet be a vaccine.

NSAC supports the JC recommendations on Research (Rec. III, A, p.17),* specifically the items relating to optimal research climate (1), quick retrieval and dissemination of pertinent information (8), stress on basic research (2), and need for longitudinal studies to include both biological and social variables.

The Joint Commission recommends ten child mental health research centers to study issues related to childhood mental health (III, B, p. 18) and includes specifically the study of childhood autism, childhood schizophrenia, from both a biological and behavioral point of view (3). Those of us who long for one such center, the prospect of ten is at first heady; but on second thought, would it be possible or even desirable to gather ten teams of researchers with all the necessary equipment to do biological as well as other research? Would it not be more efficient to have one well staffed, well equipped, well funded "academy"?

Since education is the most important and consistently successful method of amelioration for mentally ill children, there should be federal legislation to require every state to educate all of its handicapped children as a prerequisite to obtaining federal funds for education. Such legislation would help to insure state compliance with the objective of free public educational opportunity to all citizens of school age. There should be generous federal funding for such programs.

Pre-school education: NSAC vigorously supports the Joint Commission's recommendation that preschool programs should include programs universally available for emotionally disturbed and mentally ill children (Rec. II, D, 1, p.13) These programs would be continuous, year-round, and based on sound knowledge of child development.

*All references to recommendations of the Joint Commission relate to those which appear in Digest of Crises in Child Mental Health: Challenge for the 1970's, Final Report of the Joint Commission on Mental Health of Children, Inc., Fall 1969, 42 pp. However, the basis for this Statement is the full text of the Report.

Special programs within the public schools: A large number of emotionally disturbed and mentally ill children can fit, at least for certain activities, into regular classes with normal children. The term often used is "special classes." NSAC prefers the more flexible term "special programs," so that special children are included as often as possible in regular school activities, such as cafeteria, gym, music, art, playground, assembly and when they are able, classes in whatever academic subjects they can handle. The special programs should be within not only the public school system, but within the public school building. Too often, "special classes" and "special schools" mean special children are housed in school and church basements, old houses, a converted janitor's closet and other "make-do" facilities. These children should be as visible as any normal child, mingling with the normal school population whenever possible. The association is of benefit not only to the handicapped child, but to normal children, who learn to accept human beings who are different. In schools where there are special children, it is no less than inspirational to witness the matter-of-fact acceptance by the normal children of their less fortunate schoolmates. Special public schools for mentally ill and other handicapped children should be established only for grave and extraordinary reasons.

Because we feel the terrible immediacy of the problem, we have spoken about what we feel should be top priorities. Though we differ in this view from the Joint Commission Report, it should be pointed out that there are many fine recommendations in it with which we are in total agreement -- such as the need for better diagnostic and evaluation services, supportive and relief services for families, and a good section (in the final Report) on research.

We need to say, too, that the existence of the Joint Commission has called attention to the desperate condition of the mentally ill child in the United States. If the Joint Commission had done only that, it would have been worth the million and a half dollars.

# THE JOINT COMMISSION ON THE MENTAL HEALTH OF CHILDREN: ITS RELEVANCE TO MENTALLY ILL CHILDREN

Harriet Mandelbaum
Third Vice-President, Joint Commission on the
Mental Health of Children

Preaching to the converted may seem to be a waste of time to a missionary. It may not save souls, but it certainly can be soul-satisfying. For me, it is a great pleasure to be addressing an audience to whom I need not explain the meaning of autism, and who, in addition, do not have to be persuaded of the very existence of mentally ill children.

I have been asked to talk on the relevance of the Joint Commission Report to our mentally ill children, but perhaps I ought to start with my own relevance to the Commission. It seems obvious that a body appointed to develop "a program of research into and study of our resources, methods, practices of diagnosing or preventing emotional illness in children and of treating, caring for and rehabilitating children with emotional illness" should include parents of these children who know their problems and needs, and representatives of citizen organizations dedicated to seeing that services to meet these needs are provided. I was appointed to the Commission as a representative of the National Association for Mental Health, and my experience as the parent of a mentally ill child gave me a concrete awareness of the real-life problems involved in the long and difficult search for help. No one was invited to join the Board as a parent spokesman.

My oldest son is twenty-seven now, leading a productive life with a real job in the real world. His slow development from a three-year-old for whom lifetime institutionalization was predicted is described elsewhere in these Proceedings. Though public schools rejected him as uneducable and psychiatrists as untreatable, we refused to give up. The slow miracle of his progress in the private residential schools we found with such difficulty proved both wrong. We know now that his diagnosis was autism.

It's less difficult, I think, to be a parent of a mentally ill child today, but probably even more frustrating. Easier, because the diagnosis has been refined, because you can find and work with other parents who share the problems. More frustrating, because in an atmosphere of greater hope and knowledge, facilities are still tragically few.

My conclusions do not stem from my personal experience alone. The excitement of the possibilities and my dismay at the lack of opportunities led me to quit my job and join like-minded people - parents, professionals, concerned citizens - to help open doors. Through the parents I met in the League for Emotionally Disturbed Children and elsewhere, through the "graduates" of the League School and the members of the Young Adult Institute, which my son attended, I learned that my experience was by no means unique. I learned that some children made greater progress than my son, some less, and some none at all. But above all, I learned that it is better to risk failure than to deny opportunities.

I learned that psychiatry is as fragmented as children's services. The psychiatrists who were most helpful were those who did not necessarily have the answers, but offered support and compassion. The trouble with being sure of the answers is that you stop asking questions. I remember with deep gratitude Dr. Marianne Kris, who twenty years ago gave of her wisdom and time to plan a pilot day school for psychotic children, with emphasis on the therapeutic milieu; Dr. Leo Kanner, who with informed humility, urged us to try programs for our son with little to go on except hope: the willingness of Hawthorne-Cedar Knolls to take a ten year old schizophrenic boy with the risk that this strange withdrawn child might become the butt of the acting-out "delinquents"; the courage of Dr. Carl Fenichel in becoming the director of a small school for seriously disturbed children, started on a shoestring, but sustained by the determination of a few parents and the leadership of this uniquely gifted director.

But there also were, and are, among the psychiatrists, the Olympians who judge rather than help, the Cassandras with their grim self-fulfilling prophecies, the Procrusteans who fit mothers into their beds of blame-the-parent etiology. If these etiological considerations were simply a matter of theoretical polemics, they might continue on a philosophical level, but since services, or lack of them, for our children stem from these attitudes, they are of deep concern to us. Otherwise, we should not need to expend time, logic, and emotional energy on them. Hippocrates said, "The attribution of a divine character to the mentally ill serves only to mask our inability to treat them." Similarly, the acceptance of parental pathology as the cause of children's mental illness shifts the focus from the child to the parent and deprives the child of needed programs.

This matter of schools and factions in psychiatry is relevant to the Joint Commission, since it was the American Psychiatric Association which undertook the organization of the Commission, and subsequently representatives of other professions and organizations were invited to join the Board. Therefore, presenting a final report which represented a synthesis of all the points of view was a difficult, if not impossible, task. And now that the final recommendations have been frozen in print, what do they mean to our children?

As you know, the recommendations are divided into a description of an administrative network on a community, state, and national level, described as a Child Advocacy system, and an account of services and programs to be planned, coordinated, or provided by Child Development Councils. Like universal public education, it is only an instrument, and it is only in its application that we will know whether it really meets the needs of the children. It will take vigilance and active participation, you may be sure, to see that mentally ill children are adequately cared for. An important step in this direction is the provision that at least 40% of the members of the governing boards of the Councils be parents and consumers. This is a far better average than the Joint Commission itself, but its effectiveness will be tested in the power and ability of the Councils to see that services are provided.

The introduction, recommendations, and many of the chapters and reports contain unexceptionable statements and prescriptions. Nevertheless, my reaction to the Report includes some anxiety and reservations, based not only on the material itself, but on its genesis.

Early in its life, the Commission decided to shift from the emphasis on mental illness which appeared in its charge, to mental health, to meeting the needs of all children, and to "prevention". As so often has been the case in the past, programs, studies, and laws which purport to be all-inclusive almost inevitably "include out" the mentally ill child. This is illustrated in part by the fact that Task Force Five on "the organization, administration, and planning of facilities for emotionally disturbed children" designated in its preface a target population at odds with its title, opting for "maintenance of health" over "improved methods of detection and treatment".

Out of 136 pages of recommendations (not including the introduction, advocacy system, or manpower) roughly 30 apply directly to the mentally ill child, 16 of them an excellent section on research. The Introduction includes a Preamble with incontrovertibly noble sentiments and a fine Bill or Rights for Mentally Ill Children, which does not, however, include the basic right of every child to an education in whatever setting he may be. The National Association for Mental Health has urged the specific inclusion of this right many times. It may perhaps seem too self-evident, but then so do the others, and they all need re-stating. A sense of urgency is created in the Introduction relative to the plight of mentally ill children: dramatic statistics viewing with alarm the growing child population in state hospitals and the woefully inadequate care received; yet this impact is considerably diluted by the relative lack of attention these children receive in the body of the recommendations.

I am concerned with a fuzziness in the delineation of the actual responsibility of the Councils and a vagueness about the actual provision of services. So much energy and money can go into form and structure that content may be lost or simply be more of the same in a different package. The Council, we are told:

> functions as an informational service to guarantee the visibility of every child in need. It will make every effort to become acquainted with all children and families within its service area and inform them of its role, services, and activities and urge them to participate. In time, it is hoped that every

> **child in need will be known to the Council...Where gaps in services exist, the Council can contract for services at the nearest place where services are available and take steps to see that service inadequacies of its own community are promptly overcome.**

Is it likely that these non-existent services will be available nearby, and if they are, won't they have their own waiting lists? And who will provide the missing services? How? The report itself points up an almost insuperable difficulty:

> **Systems tend to be oriented to keeping the professions constant and stable rather than meeting the needs of the children being served. The systems tend to serve those clients most likely to achieve success on the agency's terms rather than those most in need. Agencies select as points of entry into the lives of children those situations which are easiest of access rather than those in which the child presents the greatest vulnerability or opportunity for change. There is a tendency for agencies to ignore or repress the informal service systems which do respond to large numbers of those in need. For example, many agencies discourage the efforts of non-professionals and parents.**

Since these established agencies will probably make up most of the councils, I cannot clearly see the leverage for change. They will continue to get support, while new effective services will continue to scrounge for funds and talented professional directors and parents will have to use their energies for fund-raising.

I am enthusiastic, of course, about the inclusion of parents in planning and operating, e.g., "It is unrealistic to expect all our problems to be solved by a few citizens with specific training and talents. Many of our current problems can never be solved by professionals: the solutions must come from parents and neighbors and from the youngsters themselves". However, there are recurring references which simply assume automatically that parents are patients instead of the allies here described. For example, under Education: "All psychotic pre-school children should have a therapeutic trial in a therapeutic nursery school with individual play therapy for the child and therapeutic work with the parents." etc. etc.. If my contributions to the Commission in its three-year life have had a leit-motif, it has been a monotonously persistent attempt to modify this attitude toward parents. Motherhood, so sacrosanct in American song, is the radix malorum to the American psycho-analysts. But perhaps they are for Motherhood and only against Mothers.

Since Prevention is invoked so often as our most desirable goal, I hope we can approach the concept with rigor and refine its meaning as it relates to mental illness. So much of what is now lumped loosely under Prevention is concerned with helping people lead happier lives, coping with problems and pressures, avoiding tensions and improving family life. All this is most desirable, but whether these factors are related to the underlying causes of mental illness is at best highly questionable. Until we have found the cause of a disease, we cannot prevent it. If our goal is indeed the prevention of mental illness, we must pursue investigations into its causes: the best scientific minds must search and research. Traditionally, until we know the cause and cure of a disease, we have addressed ourselves to alleviating its symptoms. We can ask no less for our mentally ill children. If we mean prevention of suffering, conflict, tensions, we must address ourselves to the improvement of social conditions and an end to man's inhumanity to man.

I do not mean to be negative about the report. There are many good things in it. Task Force 4, for example, has produced excellent materials and recommendations. The chapter on research is fine, if only some means can be found to implement it. There is cogent material on the dangers of deprivation to the child's physical mental health; a compelling document by the committee on minority group children. It has been estimated that the one hundred centers projected will cost 6 to 10 billion dollars for ten years. Compared to military expenditures, this is a modest sum. But at a time when health and welfare funds are seriously threatened, how will we get the wherewithal for the services once we have our network of Councils? Certainly, the mentally ill child needs an advocate, but his role and powers need considerable clarification and direction.

In chapter 6 of the report, Dr. Evoleen Rexford says that "Who speaks for the sick children? is a question which might echo across the country these days as the planners, citizens, and government agents sit down together." I devoutly hope the Councils will not only speak for them, but act.

**Mrs. Mandelbaum, a high-school English teacher from 1934-50, was the first President of the League for Emotionally Disturbed Children and also of the Young Adult Institute, and the 1961 recipient of the New York Medical Society Citizen's Award for Meritorious Service. She and her husband, Joseph P. Mandelbaum, were instrumental in the founding and continued growth of the League School. She has just retired from the second Vice-Presidency of the National Association for Mental Health.**

**Mrs. Mandelbaum's account of her son's development appears later in the Proceedings, in Parents' Panel III.**

# THE POSITION OF THE NATIONAL ASSOCIATION FOR MENTAL HEALTH

Mrs. Joseph V. Costello, Jr.
Chairman, National Association for Mental Health Advisory Council on Childhood Mental Illness

The NAMH, through its Council on Childhood Mental Illness has worked closely with the Joint Commission, with considerable overlap in personnel. Yet we were often filled with dismay that the Commission was paying so little attention to the here-and-now mentally ill child. Through perseverance and energy we were able to turn the attention of the Commission back to the conclusions of the Joint Conference held in 1968 and composed of members of the Joint Commission and the NAMH Council on Childhood Mental Illness. The results of this conference, published by NAMH in booklet form, concern themselves with a practical program composed of nine specific services -- services which, through dogged determination, eventually did end up in the main body of recommendations of the Joint Commission. These recommendations may be summarized as follows. They are of the first priority to help the mentally ill child and his family.

1. Information and referral services should be easily accessible.

2. Comprehensive developmental and psycho-educational assessment of each child's treatment and educational needs should be made early by a team.

3. Treatment and support services should be provided where indicated.

4. Special education programs should be an integral part of the continuum of service (pre-school home training, regular nursery schools, regular public school classes, special classes, special schools).

5. Rehabilitation should be provided in a planned and purposeful process of strengthening of function through special education, individual and group guidance, organized recreational and socializing experience, sheltered workshops, and pre-vocational training.

6. Residential care should be provided when necessary. Within this, milieu treatment, psychological and psychiatric services, special education, and other support services are essential.

7. Transitional services, such as partial hospitalization and halfway houses, should be available to facilitate release from hospital care.

8. There should be relief services for families of mentally ill children to relieve strain and keep the family intact. Examples of these are foster grandparent programs, baby-sitting, homemaker services, etc..

9. There should be periodic assessment, evaluation, and follow-up to insure maximum benefit to the child.

Second priority should be the appointment of a Special Assistant to the President and a Council on Mental Health. Among its first responsibilities should be the implementation of this practical program for impaired children.

Third priority should be given to the important recommendations regarding manpower, research, levels of child development, health and education services. NAMH also supports a limited demonstration program as a model for a national Child Advocate system; an advocacy program should evolve from sound experience. The demonstration centers should plan to observe the three priorities outlined above.

**Mrs. Costello has been active with the Mental Health Association for several years. On the national level, she has been Chairman of the National Association for Mental Health Advisory Council on Childhood Mental Illness for the past two years. Mrs. Costello has also been President, California Association for Mental Health, 1968-70. A native of San Francisco, she is married and the mother of three children.**

**Mrs. Costello summarizes the Position Adopted by the NAMH Board of Directors Regarding the Report of the Joint Commission, June 21, 1969. For complete details on the Position, refer to the National Association for Mental Health, 10 Columbus Circle, New York, N.Y. 10019.**

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## KEYNOTE ADDRESS

## EDUCATION FOR HANDICAPPED CHILDREN: RHETORIC OR REALITY?

Edwin W. Martin
Associate Commissioner
Bureau of Education for the Handicapped
Office of Education
Department of Health, Education, and Welfare

In thinking about the rhetoric and reality of the Federal response to the needs of handicapped children, I was reminded of the relationship that John Dewey suggested between philosophy and science. Philosophy is important, he said, because it establishes a context and tone of ideas that stimulate new perspectives for science. In the same way, the rhetoric is important that stimulates new perspectives for social programs.

Last year, Dr. James J. Gallagher, my predecessor in the Bureau, identified for the California State Federation Council for Exceptional Children the three historical stages in society's approach to the handicapped:

> **The first stage was direct rejection, sometimes by actual destruction or by physical desertion. The second stage was benevolent isolation from society...marked by the construction of massive institutions built far from cities and towns, where the handicapped often lived out a life of quiet, but non-productive dependency. The third, and present stage, is their rescue from oblivion and their restoration as part of our human resources to create new and productive contributors as part of society - not apart from society.**

The second stage described by Dr. Gallagher was with us only a short time ago. The tone of the third stage is already changing. Society can no longer think of itself as "rescuing the handicapped from oblivion". Many of the problems of the handicapped are social ones that grow out of society's responses to them, and the right to productive lives and fulfillment is not given to the majority to bestow: it is an inalienable right. This year's rhetoric emphasizes the right of the handicapped to participate in society and the obligation of the non-handicapped to restore that right. And the movement of this decade must be in the direction of programs that help the handicapped to realize their abilities and away from those that reduce them to the level of their disabilities.

Nowhere, perhaps, have our failures been greater and our rhetoric more high-sounding than in the field of education, and the problems of general education are many times more critical in the field of special education. The high costs and special demands of teaching handicapped students have made it difficult to provide them with even the minimally acceptable kind of education that was being offered to their non-handicapped peers. Individual parents, local educational agencies and even the States have come to recognize that they cannot underwrite alone the considerable costs involved in meeting the needs of handicapped children. And there is growing realization that the Federal government must step in to provide aid on the level that is necessary.

The Federal government made its first foray into the education of the handicapped in 1954, when President Eisenhower signed the Cooperative Research Act. In 1957 Congress earmarked $675,000 of its first million-dollar appropriation for research related to the education of the mentally retarded. In 1958, it provided for a comprehensive program to caption films for the deaf and one to train professional personnel to work in the education of the handicapped. By 1963, there were enough Federal programs supporting such efforts to make it worthwhile to establish in the Office of Education a separate Division of Handicapped Children and Youth, and in 1967, that Division was made into the Bureau of Education for the Handicapped. With the passage of P.L. 91-230 on April 13, 1970, all major Federal legislation relating to the handicapped was consolidated into a single Education for the Handicapped Act. And this legislative action formally recognized the handicapped as a distinct population with just claims to a share in the nation's resources.

It is the responsibility of the Bureau of Education for the Handicapped to administer this law. This law addresses itself to the more than six million handicapped children in the United States. But with a basic appropriation of only $100 million, it represents rather an attempt of the

Federal government to solicit general responses to their needs than one to provide them with actual basic support. Recognizing the reality of this situation, the Bureau is, for the present, developing its role as a catalytic agent which will, through its use of seed money in demonstration programs, in research, and in manpower development attempt to stimulate and attract additional State and local educational agency money and activities. Later, as the Federal role is increased, the Bureau will help the States to develop a number of highly visible model programs that will publicize areas of high priority and encourage further public support.

The overriding objective that dictates the policies of the Bureau is the commitment to obtaining equal educational opportunities for all the handicapped children of this nation; and, at present, less than 40% of them are being served. The Congress and the President have recognized the rights of handicapped children on a philosophical level, but we are far from assuring them on a real and individual basis. Educators and special educators hold so many conflicting positions on methods and responsibilities for teaching these children that local, State, and Federal responses are often in conflict with one another. Society has not yet learned and the educational system is just beginning to learn to relate to handicapped children as human beings who have handicaps and not as embodiments of those handicaps. In the inner cities, disadvantaged children and handicapped children are often mis-diagnosed, and everywhere the disparity between what the non-handicapped are learning and that which is taught to their handicapped peers is widening.

It is difficult for me to address a group with a major concern such as yours in autism, without a sense of embarrassment - not an embarrassment that specifically derives from my role as a spokesman for the Federal government, and its poor showing in providing funds for you, but rather a larger embarrassment as a citizen of this country who knows that far too little is being done at all levels of government - national, State, and local - for millions of emotionally disturbed children, and particularly for such a seriously and multiply-handicapped child as the autistic child.

I don't mean that nothing is being done - obviously a great deal is being done - but it is still possible for me to go into suburban counties surrounding Washington and to discover that many of them have no programs at all for emotionally disturbed children. It is possible for me to read in the newspapers about protests being made over Montgomery County's decision to develop a special school facility for adolescent emotionally disturbed youngsters. It is possible for me to read in the newspapers that in McLean, Virginia, where I live, the local citizens fought to prevent a church from providing space in its education building for a school working with handicapped children, including those who are emotionally disturbed, and that the church had to agree to build a chainlink fence around its yard before the public clamor died down. And these problems that I recount to you show me not only that we must increase State and local and Federal expenditures on autism and on other serious handicapping conditions, but also that we must convince society to view handicapped people as human beings whose handicaps are less characteristic of them than their humanity.

It has been my experience from working with handicapped children and from discussions I've had with numbers of students that our society prepares us poorly to live with anyone who is different in appearance or behavior. People seem generally to fear the unknown, and society's organizational patterns have tended to isolate the handicapped and place them in that category. For this reason, we have made as a major objective of the Bureau a program of trying to influence public opinion and public thinking about handicapped children. This is a different order of activity for us - we are used to thinking in terms of extending services directly to additional numbers of children, of training so many teachers, of developing so many kinds of instructional materials, etc., but we feel that the Bureau must begin working directly to encourage parents and teachers in their efforts to teach children to understand and not to fear other people whose skins, or bodily measurements, or ways of speaking may be different.

Increasing public understanding and interest in educational services for emotionally disturbed children has a high priority with us. And we are presently working to this end with the

National Institute of Mental Health on one of the first really important joint projects between our two agencies. For too long, educators have divorced themselves from mental health personnel, and psychiatrists and others interested in emotionally disturbed children have felt that education had no real contributions to make to them. You know differently about that and so do I; there are educational programs all across the country demonstrating that autistic children, seriously handicapped children, brain-injured children, emotionally disturbed children can and do learn. We also know from experience that after the initial treatment and support services of pediatricians, psychiatrists, and psychologists are over, it is parents who have to make the lives of their children rewarding. And the educational system should be aiding in that undertaking. One of the projects that we have supported to help parents in this regard was a joint effort by psychiatrists, clinical psychologists, and operant psychologists to teach the concepts and language of operant reinforcement to parents of autistic children, so that they could set up environments at home in which they could maintain the gains made under treatment.

I have been very encouraged, too, by the awakening of interest in early childhood education, and it has the highest single program priority in our Bureau. We must, as they used to say, through the smoke of your sister city of the South, "head these children off at the pass". And the results of projects around the country indicate that we are beginning to do so. We have had notable success, for example, with several of our projects for Head Start dropouts, who are usually children whose behavioral disorders prevent them from coping with schools, or with structured preschool situations. Within short periods of time, many of these children are being returned to regular programs. It is happening in Los Angeles, it is happening in Seattle, it is happening in Washington, D.C., and I am sure it is happening in many other places with which I am not as familiar. But it has to happen everywhere and it has to happen on a massive scale.

The other day, I was told by the Director of the Mental Health Evaluations for the city of Washington, that 10% of the pre-school children in the Head Start program would not be able to survive in the first grade because they had emotional disorders. In fact, that means that almost 10% of the inner city children in Washington will not even begin school with a chance, unless we are able to develop immediate intervention programs. And the cost of their failure to society would be astronomical. The cost of providing them with special education, would be about $1500 - $2,000 per year over the next twelve years, or approximately $25,000. The cost of maintaining them, on the one hand, over years of unemployment, and years of possible institutionalization and of losing, on the other hand, the creativity and productivity that their efforts might have contributed to society is unacceptable to a nation like ours. We estimate in money that each child saved from that pattern is worth more than a quarter of a million dollars to society in terms of reduced cost and increased productivity. And we make no pretence of being able to estimate his value as a life. I have never liked talking about people in terms of dollar signs, but we are forced into a situation where good programs are competing for limited funds, and my reluctance to use the language of cost-effectiveness is being overcome as I see how valuable it can be in arguing our case before the Congress.

When the philosophical rationales and the proper social and humanistic comments have been expressed, and after the roles have been discussed that the Bureau and State and local agencies might play in helping handicapped children, we come finally to what parliamentarians call "the Question:" given the ongoing programs we have and all of the things we have said about them, and whatever qualifications we might wish to put upon them, are we, in fact, doing the things that we say we are doing? If we have sufficient funds to help only 40% of our handicapped children, are we serving that 40% in a meaningful way?

One of the things we have been trying to do in the Bureau is to find better ways to evaluate the programs that we have now. We are using the techniques of program planning and evaluation; (1) to determine where our resources can do the most good for children across the country. (2) to assure that we are, in fact, focusing our money on those areas of high priority; (3) to assure that we are supporting the most effective programs for achieving the goals that are indicated by these priorities, and (4) to assure that we will be flexible and responsive enough to adjust to the priorities of the future.

It is important to us in the Federal government to let you know that we intend to hold ourselves accountable to you for the children we serve - their lives must be improved and enriched as a result of having been in contact with us. And your assessments, your communications, your participation as parents and advocates of these children are vital to the struggle for their rights.

Finally, in closing, I want to reinforce your efforts to work with the legislative branch in developing effective public policy for your children. I know that you have done much in this area already, and how necessary it has been for you to take your case to legislative bodies to develop the basic programs you have. That has been true of the whole history of education of the handicapped, parents have had to go to the school boards, to the State legislatures, and more recently, to the Congress for a response for their children.

I am asking you to redouble your efforts. Professional people and parents, many of us as regular citizens, have not been involved in the political process, have not known how to support public officials, how to bring information to them, to let them know about our goals. We have abdicated this responsibility and left it to others. I believe we get the kind of government that we work for and surely this is a worthy area in which to work.

Don't be ashamed of your efforts, get your Representatives to come and see the programs. Help them to understand the realities, not only the severity of the disorder, but the hope that can come from education and training.

This is important work, not just for your children and your families, but for our nation. It is important that we convert rhetoric into reality and that we have the kind of a country which demonstrates the sincerity of its commitment to the handicapped. America will not be known in history solely for its affluence or for its great technological advances; it also will be known by the record it makes in aiding the poor, the handicapped, and the weak. Your work to develop programming for autistic children, and your work with the Congress and with State legislatures, with school boards, to convince them of the importance of that mission, is work for all of America. It is a work that will improve the character of our country, and in the time when so much of our attention is focused on devisiveness, on disorder, on hatred, on killing, it is a healing work. I am an optimist - I believe we can do these kinds of things. I was very impressed by the remarks of the late William Faulkner when he received the Nobel Prize for Literature. Falkner said, and I think we can adapt it to our purposes:

"I believe that Mankind will not only endure, we will prevail."

Dr. Martin was Associate Professor of Speech Pathology at the University of Alabama Medical School and Co-Director of the Speech and Hearing Clinic before he came to government work. He is the author of numerous papers on speech therapy and the education of the handicapped.

# STRENGTHS AND WEAKNESSES OF OPERANT CONDITIONING TECHNIQUES FOR THE TREATMENT OF AUTISM[1]

by O. Ivar Lovaas
Professor of Psychology
University of California at Los Angeles

Quite early in my work with autistic children, Dr. Bernard Rimland came to visit me and introduced me to a group of parents in the Los Angeles area. At that time, it was very difficult for clinical psychologists to meet parents of autistic children without reservations on both sides. The constraints and artificialities of the office situations are well known to us all, and gives a biased picture of both the child and the family. But it is hard to play it cool around Dr. Rimland, and it's a very different experience when parents and psychologists get together in a good Italian restaurant over spaghetti and red wine, as we did that night. I got to know some people rather well. I think I started my work, then, under unusually favorable circumstances. May I here express my thanks to the parents I met then who entrusted their children to me.

Let me say at the outset that I do not have an autistic child myself, but that I do care for your children. When our work is difficult, and our progress is limited, I fall back upon this care which is the most important base of our work. I know that I am not alone in this feeling. I hope it offsets some of my mistakes.

In this talk, I would like to give you some feeling of how the behavioral psychologist may approach the problem of isolating effective treatments for autistic children. I think that our concern about research methodology is our most distinguishing feature.

We have tried to center our inquiry on those statements that are susceptible of being proved wrong, and relatively quickly. This is why I have not asked questions about the etiology of autism, on why these children became the way they are, whether the cause is environmental or genetic. I think it is reasonable to conclude that it is organic, but we can't as yet point to any decisive experiment, neither can we conceive of a procedure which would clearly distinguish between organic and environmental contributions. So I don't ask these questions at this time, not because they aren't important, but because they are not productive for our work right now. There are many similar questions which we steer clear of; for example, one can debate whether autism is a distinct diagnostic category, to be separated from child schizophrenia, retardation, etc.. I can conceive of no easy answer to that question, I am reasonably sure that we will not be able to settle it by debating it, and I have seen no data which would lead one to reliably infer that it is useful to call a particular child autistic, as distinguished from retarded, or brain damaged, or schizophrenic. We cannot point to etiological factors which isolate these groups from each other, neither can we show their differential response to treatment at this time. Ultimately, these are very important questions, but there are no answers to them now, hence the debates which these questions have given rise to have proven only minimally helpful to parents and professional people treating autistic children.

So we try to frame immediately useful questions which deal with very concrete, delimited and tangible aspects of the child's behavior. Some of these problems are very mundane and carry very little propaganda value: for example, how do you teach the child to go to the potty, how do you teach him to button his pants, how do you teach him to eat his meal in a reasonably civilized fashion, etc.. Others refer to much more complex behavior and involve questions such as how does one teach a child to speak, how to read, or to become curious about the world around him.

Consider an immediately pressing problem; consider a child who is mutilating himself, how do you stop him from doing that? We do not ask what in the past has made him, or not made him do that, but rather what can we do right now to help him? As you know, self-destructive behavior is very frequent among autistic children. In a film which I will show you, you can see some extreme forms of self-destruction. Here is a boy who hits himself so hard that he almost passes out. Here is a girl who knocks her head on sharp corners of furniture; she won't hit her head on round corners, she wants it bloody. She has done this for years, since she was three; she is now eleven. Here is a child who has over the years been biting off most of her little finger, and as you can see by the dark areas around her nails, attempted to pull out her nails with her teeth. This boy here has actually bitten off a good deal of his right shoulder; several ounces of flesh have been removed. Here you see another child, spread-eagled on his bed, and restrained on hand and foot in order to prevent such behavior from occurring. Some of these children have been restrained for most of their lives. This would be a meaningful direction to human work, would it not, just to get this boy out of his restraints?

What is a natural response of any human being--parent or therapist? It is, of course, to love, to comfort the child when he is in such pain. The question we raised, and studied with very explicit and precise measurements, was: what is the effect if you follow these natural responses? Well, on the days in which we treated the child in this way, he actually got worse, the rate of self-destructive behavior more than doubled. It is the kind of treatment which makes the attending adult feel better, but which actually was harmful to the child.

One day we treated the behavior in a different manner: quite impulsively, and without any recourse to theories of behavior or psychopathology, I cracked one of these children on her rear, contingent on her self-destructive behavior. You see, I knew her so well that she was like one of my own children, and of course, I don't let my children get away with things like that. I will never forget her face, when she turned right around, as if to say, "What kind of a psychiatric clinic is this?" But it worked. By far the most efficient way to handle this kind of behavior is to punish the child when he does it. The punishment is aversive and contingent. Some people can do this, and some can't. For those who find it difficult to contemplate physical punishment, I should say that it is also possible to get rid of many undesirable behaviors by ignoring them. We call it "extinction" in technical terms. It is a method that works very much more slowly than punishment. All the records indicate that when ignored, the behavior at first gets worse. Then, and gradually, it decreases. The process, however, takes much, much longer. You must consider that you may have to ignore the behavior several thousand times. Clearly, aversive stimuli, even by punishment which appears severe, prevents more damage in the long-run. Therefore, it is justified. By the way, self-destructive behavior seems to be like social behavior. It has a rudimentary communicative purpose, it occurs as a response to frustration, and can be strengthened and weakened by the rewards and punishments which accompany it. Our data show that the behavior is systematically related to very specific environmental events. It is, of course, sad that the children have such severe handicaps that they have to resort to such maladaptive behavior in order to express themselves. However, it is important to realize that, although one is aware of their handicap, one does not necessarily allow the children to act in this crazy manner. For those who would like to know in more detail all the work we have done in this area, I would recommend a publication of Lovaas and Simmons (1969).

Let us consider another kind of behavior which these children demonstrate in abundant quantities, the self-stimulatory, stereotyped, repetitive mode of behavior, such as twirling, rocking, spinning, gazing, tapping, etc.. All the autistic children we have seen have engaged in such behavior. So, one may reason that this is deviant behavior, and if one can understand why they behave in this manner, then one can understand something about autism. We have studied this behavior from the very beginning, but when we try to explain it, we do not have much luck. We have decided to call it "garbage behavior" because of two observations: first, if an autistic child is taught some other behavior, then that other behavior will gradually displace the self-stimulatory behavior, without your having to deal directly with it. Secondly, we know that if one takes a perfectly normal child and places him in an environment in which he has nothing to do and where he has no reason to believe he is being observed, then he will engage in self-stimulatory behaviors which are virtually identical to those which you see in autistic children. There may be some subtle differences between the self-stimulatory behavior which you see in autistic and normal children, but it is very difficult to measure these differences in an objective and accurate manner. (These differences might relate to the muscle contracting, seizure-like contortions of some of the self-stimulatory behavior in autistic children which is difficult to replicate in normals.) Another observation is perhaps of interest: when the autistic child is engaged in self-stimulatory behavior, then he appears less responsive to auditory inputs. The self-stimulatory behavior apparently blocks his response to auditory signals (Lovaas, Litrownick & Mann, 1970). The autistic child can be trained to respond in spite of the self-stimulation, but this probably delays his acquisition of new behaviors. Since the emphasis of our treatment program is to make the child look as neat and appropriate as possible, we attempt to suppress the more severe or grotesque forms of self-stimulatory behavior by the use of aversive stimuli. It is obviously very embarrassing for people to be in the company of a child who jumps up and down and ritualistically slaps his arms in front of his face: such behavior socially isolates the child and embarrasses his parents, hence the attempt to suppress it. In this regard, let me say that I think it is unfortunate that these children have been called mentally ill, since that label tends to absolve them from socially-acceptable behavior and responsibility, and therefore limits their opportunity to develop.

We are in the dark in our attempts to understand self-stimulation. Since we don't know much about it we can speculate freely about its antecedents and its causal properties. One of its intriguing features is that it apparently maintains itself independent of external reinforcement. In that sense, self-stimulation is different from self-destruction, which depends upon a source of external rewards in order to exist. We also do not get normal, appropriate behavior from the autistic children without "paying for it." However, the self-stimulatory behavior is "for free," and we would be in an unusually favorable position if we had some way of channeling the self-stimulatory behavior into normal, appropriate behavior.

It is clearly not enough to extinguish self-destructive behavior and to suppress self-stimulatory behavior. What can we do to start a child going on something else, some other activity, on the road toward the acquisition of more normal behavior? Love them? People have lavished attention on these children and seen no change. So we have designed our treatment program in which a child gets none of this love, or if love is food to him, he gets no food, unless he behaves in a prescribed and more acceptable way. What can one teach such a child? We have not found this a particularly difficult question to answer. Ask a mother who has cared for her child for years, yet he hardly notices her. How would you feel if after all these years of giving to the child, the child was to give something back to you? How about a hug? After all this one-sided giving there is no question but that he owes you one. So let's teach him a hug, let's program it, in sequential steps.

Let me show you a film where you can see how we build a hug. Here is a child, a five-year-old mute autistic child who has never recognized people around him, and who is completely unresponsive to both what he sees and hears. Here is an attending adult who has spent two years loving the child throughout his waking hours and who has never received anything in return. Here are the ingredients in this teaching situation and here is the recipe for how we mix them up: the attending adult says, "Give me a hug," which we refer to as a training stimulus since we are going to train the child in such a fashion that this request reliably elicits a hug. Since this stimulus is completely neutral in the beginning, and elicits no discernible behavior in the child, we bring about the response by simultaneously presenting a prompt stimulus. A prompt stimulus is any stimulus which elicits a behavior before you start training. At this time it is the sight of food, and one of the therapists "draws" the child to the attending adult by presenting it in the child's field of vision. As soon as the child is in the physical proximity of the attending adult, and thus approximating the hug, for example, by accidentally touching her cheek with his cheek, he gets his reinforcement. The term reinforcement, which is the third technical term we employ, is any stimulus which, when it accompanies behavior, has the function of changing that behavior. In this instance, we have him a corn flake to eat. You can of course strengthen the rewarding property of this stimulus by placing the child on mild food deprivation, and in the beginning you may have to do that. Let me tell you that it is a pleasure to work with a child who is on mild food deprivation, particularly if he has a history of being a good eater, because that is a child who is truly motivated to learn. When he is motivated you are not wasting his time or your time. In the beginning, you give this reward 100% of the time, and you give it for approximations to the desired end product. Obviously, you cannot expect a perfect hug in the beginning, and you don't hold the child responsible for a perfect hug, otherwise he would not receive reinforcement and then he would not learn anything. In an ideal situation, and this is truly a beautiful one, the child is always successful, he is receiving reinforcement, he is happy with you and himself, yet at the same time he is always learning, in gradual steps, a better and better response. We call this learning by successive approximation. Now you will notice this, that we will gradually attempt to fade the prompt; by this we mean that we will gradually remove the prompt, making it less and less reliable, so that we transfer control of the child's behavior from the prompt to the concurrent training stimulus. Eventually, the child's behavior will become controlled entirely by the adult's request for the hug. There are two kinds of learning involved here then: first, he has to learn to make a hug, that is, he has to learn the topography of a response which involves, in its final phases, cheek-to-cheek, arms around the attending adult's neck, a squeeze, general relaxation of body muscles which is associated with comfort, etc.. Secondly, he has to learn when to hug, namely, when the adult asks for one. We say that his environment has to acquire stimulus function for him. Later in the learning, you can see that we begin to gradually remove the reinforcement; to thin the reinforcement schedule, as it is technically known. This means that instead of reinforcing the child for every response, we will shift him slowly onto every second response, then every third, every fourth, every fifth, etc.. The question becomes one of sheer economics: how many hugs can you get for one corn flake? 100? 200? Eventually, the reciprocal hug itself may be enough to maintain the behavior. But it could never have got it going.

If we withhold the reward altogether, particularly in the early stages of learning, how long will the behavior last? We will see in this film that the removal of this reward brings about the extinction of the behavior. Very gradually the child loses the behavior you have taught him. The hug is first replaced with rage reactions, then with a great deal of sadness and you can see the child's first real tears, and eventually he is back to where he started from, self-stimulatory behavior. It is clear, and it is very important to know, that this behavior, like much of our own, is dependent upon explicit and reliable rewards.

We are not always, with all children, totally tied to biological rewards. One uses common sense in this instance; obviously, you do not need to use food with a child who will work for your approval. Does a behavior become self-reinforcing over time? Well, it varies according to the child and the behavior you ask for. Some behaviors they will engage in for their own sake, others not. But in general, if you remove the reward too quickly, you can count on losing the behavior. It may be that if all rewards were removed, all behavior would terminate, including that of college professors. In general, we try to shift from biological rewards to social rewards, from food to the pat on the back and a "good boy!" Sometimes we are successful in shifting from biological to social rewards, sometimes not.

Using essentially the same procedure for teaching, we can attempt to help the child acquire much more complex behavior, such as speech. We have both a film (Lovaas, 1969) and a paper (Lovaas, 1967) describing that program. How far can you go with this procedure? Well, that question is not answered yet, because we have just begun. This explicit behavioral engineering, as we like to call it, of children with deficit behavioral repertoires, is only seven to eight years old. I think it is fair to say that at the present time, if you think of growth as a 100-step ladder, we have taken the first ten steps. We have one important advantage, we understand fully how we moved those first ten steps so we can reproduce them at will. Our students do not have to start from the beginning as we did, they can go beyond this. And in that lies the importance of making verifiable statements, which I referred to in my introduction.

Are there peculiarities in autistic children which leads one to expect that they have a particular disadvantage in acquiring new behavior? Well, I can tell you that it has been extremely difficult at times to move from the prompt stimulus to the training stimulus, just as it has been extremely difficult to shift the child's behavior from being supported by biological stimuli to social-symbolic stimuli. We have designed some experiments around this and the best we can come up with is this: that these children are unusually selective in their attention to stimulus inputs. They are deficient in their perception of complex inputs. By that, I mean that if you present them with two stimuli, for example, a visual and an auditory stimulus, they will be significantly affected by only one of these inputs. Another way to say the same thing is to say that they show an extreme form of selective attention. When they hear they do not see, and when they see they do not hear. It is important to note that when the stimuli are presented singly, the child will attend to them and become controlled by them; the attentional problem shows up primarily when the stimuli occur in complex or multiple units. With these kinds of difficulties in attending to complex inputs, it is reasonable to deduce that the child will have problems in acquiring behaviors which require contiguous presentation of more than one stimulus. We can say more; if he has difficulty responding to two or more cues, then he'll have difficulty with all associational learning. Such data helps to explain the meaninglessness of autistic children's behavior. Meaningfulness requires a context. The autistic child has difficulty understanding a context because he responds only to one aspect of it. We have several studies designed to clarify this problem more fully, and if you write me and request it, I will send you a paper which describes this research and its implications in more detail (Lovaas, Schreibman, Koegel & Rehm, 1970).

To summarize the result of our treatment projects, I would say that we are probably best, most efficient and most reliable, at removing behavior. This is particularly true in the case of self-destructive behavior where, seemingly independently of how badly the child is mutilating himself or how long he has been doing so, we can essentially remove this self-destructive behavior within the first minute. The obvious disadvantage in this procedure is that many people cannot bring themselves to "punish" a child who is "sick". We have not had quite the success in suppressing self-stimulatory behavior that we have with self-destructive behavior, and my guess would be that this is caused by the non-social, perhaps internal, reinforcement which backs up self-stimulation. With respect to building behavior, it is certainly true that with the older and mute autistic children, our progress has been quite limited. As an example, the program we have for building speech in these children has been fairly well limited to establishing elementary vocabularies for requesting wants. In the case of the echolalic children, we have been more successful, but here I feel that the child already comes to the treatment situation with a large number of behaviors and our problem is more to rearrange and place them within the appropriate context, rather than to teach new topographies. The problem here may be motivational too; certainly the echolalic children can be controlled by many more reinforcers, in addition to possessing many more elaborate behaviors. There are three aspects to our progress: all the children we have seen have gained something from the treatment we have given them, and we can demonstrate that by objective data. On the other hand, the program does not turn out normal children, and should a child become normal as we treat him, then that, no doubt, is based on the fact that he had a lot going for him when he first started treatment. We do not know why he became normal. Third, the progress that we have made depends for its maintenance upon a continuous therapeutic environment. For example, in the children who we have discharged to institutions where they essentially received no treatment, it has been only a matter of weeks or months before they regress to their previous, pretreatment stage. If we treat these children a second time, then they improve very quickly, which makes me suspect that they did not forget what we have taught them, but rather, that the problem is a motivational one. Bahavior therapy with autistic children, then, may be seen as analogous to medical treatments employing hormones: the therapeutic benefit is a function of its continuous application.

I thank you for the opportunity to talk with you and tell you about some of our work. There are now programs going on in other parts of the country, too numerous to mention here. For those who are interested in following these developments, I would recommend two journals which publish most of this work; they are the Journal of Applied Behavior Analysis and the Journal of Behavior Research and Therapy. You may also be interested in reading some of the early work in this field, such as the studies of Hewett (1965), Metz (1965), Risley and Wolf (1967), and Wolf, Mees and Risley (1964), all of which were influential in shaping the form of our own program.

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**Dr. Lovaas is the author of many papers, a selection of which is cited in the following References. He is a consulting Editor of the Journal of Psychotherapy and the Journal of Behavior Therapy, Associate Editor of the Journal of Applied Behavior Analysis, and consultant to several state and Veterans Administration hospitals in California.**

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# AUTISM: A DEFICIENCY IN CONTEXT-DEPENDENT PROCESSES?

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This will be an informal communication giving some of my thoughts on autism. These thoughts are generated by similarities between the autistic syndrome and the effects of certain types of brain surgery. The similarities center on the fact that intellectual and emotional capabilities appear to become dissociated from one another. I will make a case here for the view that this dissociation is apparent only, that in fact a disturbance occurs that is basic to both interpersonal emotion and specific facets of the intellectual problem-solving process. The autistic child presents a paradox. He is not generally retarded in problem-solving ability as is the mongoloid, for instance. Nor does he display specific disorders that can be readily correlated with known neurological damage as in the cerebral palsied, spastic child. The autistic child is an enigma to his parents, his physician and his teachers.

My own encounter with paradox came while in the practice of neurosurgery. It was during the hey-day of psychosurgery when frontal lobotomy was an accepted routine procedure. Psychiatrists would certify a patient for surgery, the surgeon would, frequently sight-unseen, deploy the leukotome: a long dull knife blade, an egg beater or an ice pick, depending on his preference. Often surgeon and patient did not become acquainted until after the operation when dressings had to be changed, etc..

I wanted no part of such doings. My surgical training had insisted that I make my own diagnoses before cutting and that the most basic principle of medical care was "prime non nocere"--"first of all do not injure". But how did one go about diagnosing emotional disturbance and how did one evaluate whether one had injured a patient's mental makeup?

These questions led me first to devise my own diagnostic procedures and tests of perceptual and motor skills and problem-solving capacities. I quickly found limitations to these homemade procedures and tests (e.g. many of the nurses I used as control subjects did as poorly as lobotomized patients) and so turned to professional clinical and experimental psychologists for help. Despite this, I found the problem of evaluating the lobotomy procedure terribly complex and decided that first some basic research on non-human primates was needed in order to properly formulate the questions that must be asked.

Meanwhile, others were exploring the effects of surgery on man's frontal lobes. The most impressive research was that of the Columbia-Greystone group directed by the neuroanatomist Fred Mettler (Mettler, 1949). Lawrence Pool performed selective partial ablations of the frontal cortex of patients who were tested and observed by a team of specialists headed by Robert Heath, a psychiatrist. This research, as did most others of its sort, showed minimal effects of the psychosurgical procedure on tested performances, but dramatic changes in "personality," "interpersonal relationships" and other such difficult to specify clinical entities.

My experience with non-human primates, chimpanzees and monkeys, was just the contrary, and thus the paradox. Though some specific changes in emotionality such as the shortening of the duration of a reaction to frustration were demonstrable after frontal surgery; the impressive effect of the procedure was on problem-solving ability. Not all sorts of problem solution were impaired--sensory discriminations, for instance, remained intact. The difficulty of the frontally lesioned primate was manifest on problems such as delayed response and delayed alternation in which the cue to proper performance is no longer present when a choice has to be made. Choices in such problems are dependent on recall of a cue that was presented or a behavioral outcome that took place some seconds or minutes before the opportunity for choice is given. Since frontally damaged non-human primates failed this task, the interpretation was made that the frontal lobes were critically involved in recall, in short-term memory.

In short, paradoxically, frontal surgery in man affected personality, not memory in any obvious fashion; in non-human primates such surgery altered short-term memory, not personality in any obvious fashion.

The paradox was compounded some years later when just the reverse situation developed as a result of surgical invasion of the temporal lobe of man's brain, resections of the limbic structures (amygdala and hippocampus) which form the medial portions of this lobe. Now severe deficits in man's memory were unaccompanied by any obvious changes in personality. In monkey, by contrast, after resection of limbic structures problem-solving impairments were initially extremely difficult to demonstrate while changes in temperament, tractability, sexuality, etc. were profound and dramatic.

The easy explanation for the human vs. non-human discrepancies has recourse to the simple fact that man is, of course, different from his non-human primate relatives. But this explanation is no explanation but only a restatement of the findings. What the scientist is after is some basic conceptualization that can account for the double paradox. To this end, tests have been refined and better tailored to the organism being tested. Evaluations of changes in temperament and personality have been quantified to provide more sensitive indices of change. Though the story is still incomplete, twenty-five years of research has produced a yield. Here are some of the highlights in results and my interpretation of them:

### A. Differentiating Frontal and Limbic Structures from the Rest of the Primate Forebrain:

1. The problem-solving tasks impaired by frontal damage are also impaired (though not all tests show damage to all structures) by limbic damage, but never by damage to the remainder of the brain cortex (Pribram, 1969a).

2. The converse also holds. The type of discrimination task impaired with damage to cortex outside the frontolimbic brain remains intact following frontolimbic damage.

3. There is good anatomical and neurophysiological evidence that links frontal cortex to limbic structures (Pribram, 1958; Nauta, 1964).

4. When non-verbal tests are used a graded series of impairments in the delayed alternation type of problem-solving can be demonstrated from monkey, through chimpanzee to man (Pribram, et al., 1964; Poppen et al., 1956).

These experimental results suggest that the primate forebrain can usefully be divided into a frontolimbic core and an outer shell. It is as if we had two separate brains, one inside the other, each with its own function.

B. Specifying the Difference in Function Between Frontolimbic Core and Outer Cortical Shell:

1. As noted, the impairment following frontolimbic damage involves short-term memory, that following damage to the outer shell involves perceptual and motor discriminative skills (Pribram, 1969b).

2. The defect in short-term memory does not result primarily from a more rapid decay in memory trace, but from a failure to register what needs to be remembered (Pribram and Tubbs, 1967).

3. This impairment of registration shows up when the demanded behavior depends on changing conditions. The changes act as distractors interfering with the memory process (Grueninger & Pribram, 1969; Pribram, 1969a). Try yourself to remember a telephone number just looked up when an interruption intervenes before you can make your call. Even in the intact human recall is severly limited.

The results of this set of studies can be conceptualized as follows: We have two modes of operating in our environment--one mode uses signs and the other uses symbols. Signs are derived from consistencies in a situation: an apple is an apple whether on a tree, in a fruit basket or rotting on the ground. Symbols on the other hand, have different meanings in different situations. Their meaning derives in each circumstance from what the organism brings to that circumstance, his current state, the history of his reactions to similar circumstances. Stated more formally, signs are context-free attributions signifying the constant aspects of the environment; symbols are context-dependent constructions symbolizing the organism's sensitivity to changes in the environment. The brain's outer shell is involved in making signs; its frontolimbic core in making symbols.

## C. Is it then possible for Non-Human Primates to Make Signs and Symbols?

1. The Gardners (1969) at the University of Nevada have trained a young chimpanzee named Washoe to communicate by means of a hand signalling system used by the deaf and dumb--American Sign Language. Washoe has mastered 150 such signs, invented a few of her own, and can string signs together in a haphazard order: e.g. you-pet-me; pet-you-me; me-you-pet, etc.. Washoe is as yet capable of none but the most rudimentary communication when meaning is dependent on the order in which signs have to be made. Nor is her vocabulary comparable to that of a deaf and dumb human child of the same age. Nonetheless, the Gardners' and Washoe's achievement shows beyond doubt that chimpanzees can communicate by means of signs.

2. David Premack (1970) of the University of California at Santa Barbara has taught a young chimpanzee, Sarah, to communicate by means of symbols. Premack developed a hierarchy of arbitrary tokens which take meaning from the situation in which they appear--much as in one form of the delayed response task and a poker-chip chimpomat which was developed from it during the 1930's. Sarah has also a vocabulary size of around 150 and has shown evidence of communicating when meaning is derived from order. Again, by comparison to a human child, Sarah's accomplishments are rudimentary, but nonetheless striking.

These experimental results, just like the earlier ones on the effects of brain damage on problem-solving, indicate a continuum of primate problem-solving ability and brain involvement in this ability. The paradoxical effects of brain damage on memory and emotion ought not therefore to be explained away by taking refuge in the fact that monkeys, chimpanzees and man are grossly different.

So, how can the paradoxical effects of brain damage on memory and emotion be explained? They cannot be completely, at this time. But this much can be suggested. Both short-term memory and interpersonal emotion are context-sensitive, symbolic processes. The way in which a particular situation becomes symbolized is different for man and non-human primate, in part because man has so much greater linguistic facility. At present, there is little evidence that either Washoe or Sarah can make propositional utterances upon which human language is based. In non-verbal communication, the non-human primate also shows limitations in the complexity of the context to which he can react. These may well be the reasons why monkeys, chimpanzees and humans react differently when context-sensitive behavior such as memory recall and interpersonal emotion are manifest.

In summary, I believe that the paradoxical effects of damage to the frontolimbic core of the brain result from the fact that these core-brain systems are involved in context-sensitive behaviors. Independence from context leads to the identification of consistent environmental attributes which are more or less the same for all individuals irrespective of genus. When, however, meaning depends on context, the organism's particular memory and emotional makeup become critical.

So now to return finally to autism. I want to propose the hypothesis that the autistic child is deficient in context-sensitive processes, and that this deficiency should declare itself both in problem-solving and in interpersonal emotional reactions. The hypothesis is readily tested and if evidence in support accumulates, one would next wonder if for one reason or another the frontolimbic corebrain of these children has become damaged and if the damaging agent can be found and eradicated. In the meanwhile, remedial steps can be taken. Sensitivity to context can be enhanced through making the child aware of the context-dependency of aspects of situations and training appropriate response mechanisms. Further, if parents, physicians and teachers know with what specific difficulty the autistic child is coping, allowances can be made, the child becomes understood, and thus less of an exasperating paradox. This charts my path toward hope. Does it ring a responsive chord in you?

**Some of Dr. Pribram's many articles on brain organization are cited in the following References. He is also author of Brain and Behavior (Penguin; paperback: available through NSAC), the four volumes of which treat Moods and States of Mind, Perception and Action, Memory Mechanisms, and Adaptation. Another book will be published soon.**

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# THE AUTISTIC CHILD AS TEACHER AND LEARNER

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My early experience with autistic children was both frustrating and challenging. As Principal of the UCLA Neuropsychiatric Institute School, which opened its doors in 1961, I was charged with the responsibility for providing an educational program for all of the 42 inpatient, severely emotionally disturbed children in the hospital. With a fine staff of four dedicated teachers, an attempt was made to develop a school program with 'something for everyone.' During the course of the past ten years, I have learned the range of 'somethings' that must be covered in a truly individualized, special education program and the range of characteristics and problems presented by the 'everyones' who make up the population of an inpatient psychiatric hospital. As I reflect back over this period, I begin to appreciate how much I learned about teaching and learning from the autistic children who entered our school.

Perhaps the most important thing I was taught by the autistic child was that he was first and foremost a learner and only secondarily a candidate for ominous labels such as infantile autism, psychosis, schizophrenia, or brain damaged. This seemingly simple notion has had a profound effect on my understanding and teaching of all exceptional children. Traditionally, special educators have been presented with children who had serious learning and behavior problems by physicians and psychiatrists who emphasized that the child was "defective", had a "disease", or was "handicapped". This was to be expected since the medical frame of reference aims toward placement of an individual's problem in a diagnostic category. Whatever usefulness such a practice has in terms of legislation and classification, it is essentially useless when it comes to teaching in the classroom. This dilemma can be illustrated by means of a bridge building analogy. When a child is diagnosed 'autistic', this diagnosis emanates from a medical-psychiatric base. When a child is called a 'learner', his label originates from an educational base. These two bases exist across from each other, separated by a chasm which must be bridged if any relevant understanding of the child is to truly emerge. Traditionally, we have attempted to initiate bridge building efforts from the medical-psychiatric side. We label, classify, diagnose, evaluate, and then knock on the classroom door on the other side to introduce the teacher to 'Johnny Jones who is autistic' or 'Mary Smith who is brain damaged'. I remember my concern about being sent autistic children in the NPI School, who were not good candidates for psychotherapy, recreational therapy, or occupational therapy and who seemed inaccessible and non-teachable individuals. There was a sense of futility and hopelessness connected with trying to teach a child with the indelible label of 'autistic'. It was when I realized that the locus of the bridge building was all wrong and that I must start the bridge from the educational base that my enthusiasm for teaching began to grow. Let me take a look at the autistic child in the broadest context of learning, assess what he needs to learn, what he is ready to learn, and what he can be successful learning and then build the bridge back to the medical-psychiatric base with an introduction of "Johnny Jones, a learner who must be helped to establish eye contact" or "Mary Smith, a learner, who needs help in learning to follow directions".

The second thing I was taught by autistic children was that every child, no matter how inaccessible and resistant, is ready at any time to learn something. If you can set your sights on such 'thimbleful' accomplishments as 'eye contact' and resist preoccupation with global, 'bucketful' notions of 'affectual responsiveness' and 'communication', we can teach any child 'something'. The field of behavior modification has perhaps made its greatest contribution to special education by instilling an optimism about teaching children complex behaviors in small increments; of moving toward bucketful goals through attainment of thimbleful objectives. In 1798, Itard, a famous French physician who can rightly be called a primitive behaviorist attempted to teach the "wild child", a wolf-child who had lived as an animal for most of his 12 years in the forest of Aveyron. The boy may have been severely retarded, brain damaged, or autistic, but Itard was inspired with the notion that given enough time and sensory training he could make the boy normal. After five years he gave up, partly because normalcy had not been achieved. However, the actual teaching of small but exceedingly significant behaviors, such as cooperative responding on cue had made a marked difference in the boy's overall adjustment. Today we have recaptured some of Itard's inspiration and optimism in the operant conditioning programs which have been instituted for many exceptional children.

The third thing I was taught by autistic children relates to the reaction of Itard when his efforts to teach his pupil to be 'normal' failed. I learned that I would have to be comfortable accepting the notion that I was probably never going to cure anybody, but that in every case, I could make a difference. Itard gave up trying to teach the boy to speak when he was only successful getting him to make unrelated sounds when confronted with objects such as a glass of water--not the precise spoken word. Today we might well settle for any vocal utterances in reference to an object and systematically attempt to shape such an utterance gradually toward the desired word. Speech training with autistic children has been frustrating because precise and spontaneous language may never appear despite long and exhaustive training sessions. But what often happens makes a difference. Children who were previously non-verbal or who used primitive, coercive vocalization to get their needs met are perceived in a much more positive manner by others in the environment when they learn simple labeling words and phrases. Some say, "But it's not true language." I would say it is a significant accomplishment aimed at placing the child in a position to receive much more favorable interaction with others in the world about him. No cure, but an unmistakable difference has occurred.

Having been taught by autistic children that I could trade ominous medical and psychiatric terminology for a single label 'learner', that they were at all times ready to learn something provided my expectations were appropriate, and while I would probably never cure them, I could always make a difference, I could share what I found useful with respect to the autistic child as a learner. To begin with, I needed a framework in which to view the autistic child as a candidate for learning something. This would help me firmly establish my position as a bridge builder from the educational base. After observing and working with autistic children for some time, I formulated a six step hierarchy or developmental sequence of educational goals which seemed to describe the stages of learning through which all children must pass if they are to be successful in learning and school. The first three levels described basic readiness behavior: *attention* (looking and listening to teacher and task), *response* (starting, working and maintaining response), and *order* (following routines and directions). While for most children these behaviors are taken for granted in a teaching situation, I found that each level might take considerable effort to accomplish with an autistic child. But such efforts eventually paid off because the child who is an attender, doer, and direction-follower is well on his way to learning skill and content. The second three levels described areas of content which children must learn: *exploratory* (learning accurately and thoroughly to understand and explore the environment), *social* (learning how to gain the approval and avoid the disapproval of others), and *mastery* (learning language and academic skills).

In looking at the autistic child as a learner, we first decided which levels he needed help on, described him in terms of what he could do and needed help to learn (not in terms of what he could not do a la 'handicap' or 'disease') and then went about trying to teach him something.

To accomplish this I learned I had to take three important factors into consideration: 1) the type of task, 2) the type of reward for learning which was meaningful to the child, and 3) the conditions under which I presented the task (when, where, how, how long, how well). Any effective educational program for autistic children must have a wide range of curriculum material available starting with near-zero in complexity and moving on up. It must be prepared to offer the full range of rewards from tangible such as candy, to multisensory stimulation, to social approval, to knowledge of results or grades. And it must be ready to alter the conditions of learning (where the child works, what time of day, how he is to do the task, how long he should work, and how well must he perform to reach a criteria of success) in an extremely flexible manner. Thus, I found I could select behaviors which were educationally relevant, create tasks leading to improvement in these behaviors, and insure participation of the autistic child through provision of a wide range of rewards and maintenance of highly flexible structure or conditions.

Much of what I was taught by the autistic child and what I came to know of him as a learner is just plain, educational good sense. But because we often met on the level one of learning, where I could see far more clearly the basic ingredients of teaching and learning, my lesson was never forgotten and I have since been able to help other exceptional children on a variety of other levels because of my experience with autistic children on level one.

**Dr. Hewett began his professional career as a teacher in the Psychology Clinic School at the University of California, Los Angeles. He is Chairman of the Area of Special Education at UCLA and Head of the Neuropsychiatric Institute School. He is the author of The Emotionally Disturbed Child in the Classroom: A Developmental Strategy for Educating Children with Maladaptive Behavior (Allyn and Bacon, 1968). He has written many papers on special education. Four of these ("A Hierarchy of Competencies for Teachers of Emotionally Handicapped Children," "The Autistic Child Learns to Read," "Establishing a School in a Psychiatric Hospital," and "An Experimental Reading Program for Severely Emotionally Disturbed, Neurologically Impaired and Mentally Retarded Children") are newly available in Educating the Emotionally Disturbed Child, H. Harshman, ed. (Crowell & Co., 1968). Dr. Hewett may be seen in action in the remarkable film, "Autism's Lonely Children."**

# THE INSTITUTE FOR CHILD BEHAVIOR RESEARCH STUDY OF HIGH DOSAGE VITAMINS AS A METHOD OF TREATING SEVERELY MENTALLY ILL CHILDREN

Bernard Rimland
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One of the functions of the Institute for Child Behavior is to serve as an information clearing-house for parents and professionals around the world interested in research on the cause and treatment of severe behavior disorders in children. Each year we receive communications from hundreds of people from many lands asking for information and telling us what has and has not worked to help the child or children with whom they are concerned. A truly amazing variety of ideas have been tried out--ranging from music and shadow-therapy through psychotherapy and operant conditioning to colonic irrigations and spinal adjustments. It doesn't take long to develop a skeptical attitude about most of these "breakthroughs".

Very few of the innovations have sufficient positive evidence behind them to earn our endorsement. Five years ago, I was sufficiently impressed with the usefulness of operant conditioning to make it the basis of my speech at the very first meeting of NSAC. Indeed, one of the reasons for my calling together the East Coast parents and founding NSAC at that time was that I felt it urgent that parents and interested professionals learn about operant conditioning, and start using it to help the children. Operant conditioning is now almost a household word for most of our families. It seems hardly possible that only five years ago it was practically unknown. I'm sure that the operant conditioning workshops set up in various cities by groups of NSAC parents, with the help of Dr. Lovaas and Dr. Lindsley, have had much to do with the wide acceptance of operant conditioning today.

Today I want to tell you about another innovative treatment technique that I think holds high promise. In 1966 I began to hear from various parents who had begun to experiment on their own mentally ill children, using quite large amounts of certain harmless, water soluble vitamins.

Their incentive for starting to do this was their disappointment and discouragement with the usual treatment methods, coupled with the articles appearing in the New York Times and elsewhere about the work of Drs. Abram Hoffer and Humphry Osmond, who were reporting successful use of massive dosages of certain vitams on adult schizophrenics.

At first I was very skeptical about the claims that some of the parents were making about improvement they saw in their children. As you know, these children spurt ahead or fall apart periodically for no discernible reason, and whatever treatment is being used at that time gets the credit, or the blame. But as the letters accumulated I began to get more interested in the reports. For one thing, the parents were often reporting changes in behavior that were clearly tied to the raising or lowering of the dosage level of some of the vitamins. Also, even though most of the parents didn't know each other and were trying quite a variety of vitamins, the same small group of vitamins were being mentioned again and again. And as the number of parent-experimenters grew, it began to include more parents whom I knew personally to be highly intelligent and reliable people. I then contacted a number of doctors in California and on the East Coast whom I knew had been experimenting with vitamin therapy. What I learned convinced me that even though my doing so would generate scorn and antagonism in certain quarters, I could not in good conscience fail to pursue this lead.

Before going on to describe the vitamin study itself, let me bring in a few important related points.

First, with the exception of vitamins A and D, which can in some people be harmful if taken in large doses for an extended time, there is little or no danger in taking large quantities of vitamins. Most vitamins are soluble in water, and the body merely escretes what it doesn't use.

Second, the commonly held belief that everyone gets all the vitamins he needs by eating a normal diet is sheer nonsense.

Most of us can get along quite well, apparently, without supplementing our vitamin intake, but even among normal well people there is an enormous range of individuality in vitamin needs. A range of 2,000 per cent in vitamin requirements from one person to another is not uncommon, as biochemist Roger Williams has pointed out in his book Biochemical Individuality and elsewhere. Further, there are well known disorders which stem from just such differences in vitamin requirements. Every physician is acquainted with vitamin D resistant rickets, where the child sometimes needs hundreds of times as much vitamin D as the normal child. Since 1954 there have been discovered about twelve inherited diseases which require massive dosages of specific vitamins as the major form of treatment.

Third, again contrary to widespread belief, there is a sizeable body of scientific literature, including both control group studies of vitamin effectiveness and laboratory studies on vitamin metabolism which demonstrate beyond any doubt that at least some forms of what is called mental illness are closely linked to biochemical errors in the body. For those interested in learning more about these matters, let me recommend the book Orthomolecular Psychiatry, edited by Linus Pauling and David R. Hawkins, published by Freeman early in 1971. My chapter in that book provides not only a more comprehensive report of the ICBR vitamin study than can be presented here, but also presents what I believe to be a thorough review of the scientific literature on vitamin therapy of mental illness, especially as it pertains to children. If anyone tells you that there is no scientific basis for believing that high dosages of vitamins may be useful in treating mental illness, he is simply admitting that he has not done his homework. There is by now a substantial and impressive body of data on the subject.

After deciding to investigate the problem, I sent a questionnaire to the approximately 1,000 parents and professionals then on the Institute mailing list to locate as many people as possible who had tried the vitamin approach. By analyzing the data from the 57 parents and seven physicians who responded in detail, we evolved the selection of vitamins and dosages used in our study.

After consulting several nutritionists, biochemically oriented psychiatrists and biochemists, we decided to start with a potent multiple B vitamin tablet plus several grams per day of vitamin C. After two weeks, two B-vitamins, niacinamide and pyridoxine, were added, each in quantities several hundred times the usual dosage. Finally, after two more weeks, pantothenic acid (another B-vitamin) was added. The actual dosage levels used were determined by the weight of the child. The subjects of the study were the children of the several hundred parents from various parts of the U.S. and Canada who indicated, in response to our mail survey, that they would like to participate.

The study took about 4½ months per child. After three months on the vitamins, a "no-treatment period" was scheduled so that any changes resulting from discontinuance of the vitamins could be observed. The vitamins were then reinstated briefly. The parents completed a simple one-page form describing the child's status every two weeks, and every month a similar form was completed by the child's physician. The parents also completed a more intensive questionnaire at the conclusion of their part in the study.

Although all the vitamins used were non-toxic, even in large quantities, it was required of the parents that they obtain the participation of a physician of their choice, to guard against the possibility of an adverse reaction and to provide an independent opinion on the child's response.

By June of 1970, when we had to begin analysis of the available data for the purposes of this report, we had received complete data, including the final report, on 190 children. Additional reports have continued to come in, and they are being held for later alalysis. There is a large amount of information for every child in the study--detailed once and twice-a-month doctor and parent ratings on speech, eating, sleeping, tantrums, alertness and so forth, as well as an extensive tabulation of positive and negative side effects. These data occupy some 20 IBM cards per child. To analyze them will require a great deal of time and effort. For the moment, we have analyzed only a single score, ranging from a possible 99 (meaning phenomenal improvement) to a possible 10 (meaning great deterioration of behavior). These gross improvement scores were assigned and independently checked by two judges. Discrepant or ambiguous ratings were resolved by discussion or removed from the analysis.

Before giving you the results of the statistical analysis, I must tell you the rationale underlying our very unusual experimental design.

Our choice of a design other than the traditional control-group-and-placebo design has attracted a good deal of criticism from people who don't realize that there may be better alternatives. There are many reasons for deciding against the traditional design. The most important reason is that this design presupposes that the subjects constitute a homogeneous group.

It is my firm conviction, that very little progress can be expected in finding cause and treatment for mentally ill children until the large group of children now loosely called "autistic", "schizophrenic", "psychotic" or "severely emotionally disturbed", can be subdivided in a scientific way into smaller homogeneous subgroups. As Dr. Leo Kanner, who discovered and named "infantile autism", has pointed out, for centuries medicine could make no progress against the disease known as "the fevers". It was not until "the fevers" was broken down into separate syndromes or disease entities such as malaria, diptheria, tuberculosis, cholera, etc. that progress could be made toward finding causes and cures. Mental retardation provides an example closer to home--until it became possible to fractionate the mass of "retardates" into smaller groups such as PKU, cretinism, galactosemia, mongolism, etc., it was hopeless to try to devise means of prevention or treatment.

I believe the children loosely called autistic or schizophrenic actually represent a dozen or more different types of disease, each with its own cause. It is essential to develop the means for finding the various subtypes of autistic-type children, and I have been involved in research on this problem for some years. In a recent study at ICBR, we located several hundred case records in our files where two or more professionals had applied diagnostic labels to the same child. The agreement between the diagnosticians was almost random. A child called "autistic" by diagnostician A was just as likely to be called "schizophrenic", "retarded", "emotionally disturbed", or "brain injured" as "autistic" by diagnostician B. Labels were applied as indiscriminately as though they had been pulled out of a hat by a blind man--a sad state of affairs.

(What has all this to do with the vitamin study? Patience, please--you'll see.)

We at ICBR have made some significant progress on this problem of diagnosis. Our Diagnostic Questionnaire Form E-2 asks many questions about the child's birth history, development, and symptomatology. It is designed for completion by the parents, and ultimately for analysis by computer. We have already collected over 2,000 Forms E-2 from parents throughout the world.

About a year and a half ago, on learning that Dr. Mary Coleman of Children's Hospital in Washington, D.C. had been doing some interesting biochemical work on problem children, I arranged with her and her colleagues to perform some of their highly sophisticated blood tests on a small group of autistic children in the Washington, D.C. area who formed, according to Form E-2, a homogeneous subgroup of children. Dr. Coleman reported to me that these children showed a striking abnormality in the capacity of their blood cells to process an important substance known as 5-HT, when compared with normal children. This study was reported in the April 25, 1970 issue of the British journal Nature.

I then sent her a second group of children, all of whom might loosely be called autistic, but only half of whom actually resembled the first group, in terms of their scores on Form E-2. Without knowing in advance which child was which, Dr. Coleman and her colleagues were able to identify almost perfectly by means of their blood test the small subgroup whose names I had sent her in a sealed envelope. The second study is now being written up for publication. Dr. Coleman is now doing experimental work designed to correct, if possible, the biochemical error she has found.

I have gone into this much detail to impress upon you the importance of accurate diagnosis in arriving at appropriate methods of treatment, and to convince you that Form E-2, while it may not be perfect, does contain information useful in classifying the children in medically meaningful ways.

Meanwhile, back at the vitamin study--

For each child enrolled in the vitamin study, we had required the completion of several research questionnaires by the parents, including Form E-2. Our hypothesis was that only certain subgroups of the children would be helped, while other subgroups, because the cause of their problem was not related to their vitamin requirements, would show no benefits. We assumed that the information on Form E-2 was sufficient to permit a computer to classify the children into clusters that would show differential response to the vitamins.

I will not trouble you here with many of the details of the statistical analysis, which is presented more fully in my chapter in Pauling and Hawkins' Orthomolecular Psychiatry. Briefly, through the use of his highly sophisticated computer program Normix, John H. Wolfe of the Naval Personnel and Training Research Laboratory in San Diego was able to classify the 190 children into six homogeneous subgroups, or clusters. The clusters were formed without knowledge of how well the children had responded to the vitamins. After the clusters were formed, the vitamin improvement scores were entered into the computer and the mean improvement score for each cluster was determined.

The differences between the mean improvement scores for the six groups were found to be significant at the .02 level. That is, there was only one chance in 50 that the groups means would be found to be so different if only random factors were at work. It can thus be said with a high degree of assurance that the vitamin treatment does in fact importantly influence the children's behavior, and that just as predicted, certain subgroups of children respond much more strongly than others.

A similar analysis was done for me by Dr. James Cameron of Napa State Hospital in California, and an even more advanced type of analysis was performed by Drs. Raymond Christal and Janos Koplyay of the Lackland Air Force Base in Texas. These analysis also showed the results to be highly statistically significant. There is no reasonable explanation for such findings other than the vitamins do help some children.

One of the chief advantages of the type of design we used is that now we know that we can take the more than 2,000 E-2 forms on file at ICBR, subject them to computer analysis, and tell whether each child is or is not likely to benefit if placed on the vitamin regime we used. In fact, our next study will do just that. Some people will not believe our results because we didn't follow the traditional double-blind placebo pattern. We now plan to use a placebo group--but on cases predicted by computer as likely to respond or not to respond to the vitamins.

The next step in our analysis of the data collected on our group of 190 children will be to do a fine-grained computer analysis of the findings to see if we can determine which vitamins were most helpful for each subgroup. Our use of four vitamins is in effect a "shotgun" approach, and now we need to narrow our aim. Unfortunately, this statistical analysis hasn't yet progressed very far, so I'll have to give you gross results.

The table below shows the distribution of the overall improvement scores for our completed cases.

Table 1

Summary of "Overall Improvement" Ratings

| Category | Scores | Cases | Per Cent |
|---|---|---|---|
| Definite Improvement | 70-99 | 86 | 45.3% |
| Possible Improvement | 50-69 | 78 | 41.0 |
| No Improvement | 40-59 | 20 | 10.5 |
| Adverse Effects | 10-39 | 6 | 3.2 |
| | | 190 | 100.0% |

First let me discuss the "adverse effects" portion of the table. Actually, there were more than six children whom the vitamins seemed to worsen, but a number of these were withdrawn from the study. At the moment we can't tell, unless the parents write us about it, whether a given child was withdrawn from the study or whether the parents are simply tardy in sending in their reports.

The adverse effects usually consisted of irritability, hyperactivity and sleeplessness. In most cases such early adverse effects disappeared after a few weeks on the vitamins. In other cases the problems persisted until the dosage levels were lowered or the vitamin treatment was stopped. The problems invariably disappeared within a week or so of stopping the vitamins, in those cases where the parents decided to discontinue them.

A quite unexpected side benefit of the vitamins was, in many cases, an improvement in the child's physical well-being. Quite a few parents reported such things as improved skin condition or hair texture, better muscle tone, and the cessation of teeth grinding. But of course, what is of most interest is the behavioral improvement that constitutes the basic reason for doing this study. In many children the improvement was striking. It shows up most clearly in contrasting the behavior of the child during the several months he was on the vitamins--during which time there was often a gradual improvement--with his behavior during the no-treatment-period when the vitamins were suddenly stopped.

Here are a few examples of such changes as reported by the parents: "Frustration level extremely high without the vitamins. Much yelling and irritability. Has to be given directions three times instead of once. Changes were evident after three days of no vitamins and grew worse each subsequent day...I resumed vitamins on the 14th day."

"On August 5th (10th day of no-treatment period) both parents, who had been keeping separate notes, agreed that marked deterioration of behavior had occurred. William seemed to have withdrawn into himself; he no longer exhibited the lively interest in the world around him that had marked the previous month. His newfound willingness to cooperate and to obey such directions as he understood disappeared rapidly. His old repertoire of mannerisms and bizarre hand motions and positions, which had been waning, reasserted itself with a vengeance..."

"Harriet seems to be progressively less social with us. She is starting to retreat to her room for longer periods, as she did before she started the vitamin therapy."

"Mary has been off the vitamins for two weeks. Her speech hasn't deteriorated, but all the annoying noises...have returned. Her skin tone isn't as good and the slightly bluish transparency to her facial skin is again noticeable. She is having trouble focusing her eyes and the pupils appear dilated and her expression is far off and dreamy, jaw slack..."

"He stopped taking the vitamins exactly five days ago. I never expected the definite reaction that has gradually shown up without a doubt during these last five days--slowly at first and then increasing at an amazing rate. His doctor is on vacation and we cannot see the substitute doctor until next Thursday. However, I took it upon myself this morning to start him again on the complete dosage. I only hope it will relieve his present symptoms soon, symptoms that cannot be traced to anything short of not having the vitamins for these few days.

He gradually showed improvement in every area on the checklist--even those I may have noted as no behavioral improvement, because now in those areas he has badly regressed. He is agitated and crying practically all the time, shaking nervously, hiding under blankets, tapping on things with spoons, getting into things he hasn't been getting into and that he shouldn't get into, eating poorly and away from the family table, making continuous odd noises and seems to be suffering physically from some internal misery. Without a doubt, I trace his former improvement to the vitamins. He became calmer, seemed normal in public, didn't make noises, and verbalized sensibly, socialized more, was very much, much better.

Excuse me if I've been verbose. I just want to explain fully the sudden change when the vitamins stopped."

The foregoing are just a sample of the reports in our files. There are many, many more.

I think you will agree with me that we are on the right track, for a least a good number of our children. While we are still a long way from having all the answers, we have accomplished an important first step. As our analyses and studies continue, we will develop a great deal of further, needed information.

This approach seems a lot more productive than the old one of "blaming the parents", doesn't it?

Both parent and professional Dr. Rimland is the Founder of NSAC and a member of our Professional Advisory Board. He is the author of Infantile Autism (available through NSAC), 1963 Winner of the Century Pschology Series Award, and of numerous articles. He is Director of the Personnel Measurement Research Department, U.S. Naval Personnel Research Activity, San Diego.

# WORKSHOP PRESENTATIONS AND PARENT PANELS

# AUTISM, MENTAL RETARDATION, BRAIN DAMAGE
## OBSERVATIONS WITH THE TALKING TYPEWRITER

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New York State Department of Mental Hygiene

The "Talking Typewriter" or Edison Responsive Environment (ERE) was made available to an autistic child for the first time in 1964 at the Mary Imogene Bassett Hospital in Cooperstown, New York. It proved to be a useful instrument for programming instructional materials for mentally handicapped children. It was even more valuable in providing a "diagnostic classroom" for the better understanding of the dynamics of childhood autism.

The following comments were prompted by the observation of 65 autistic children at the ERE Center in Cooperstown, 1964-66, and confirmed by later observation, 1966-70, of several hundred autistic children who had not access to the "talking typewriter". The latter were seen in clinics, at home, in public or private institutions and came from various parts of the United States including Alaska and from several foreign countries.

All met accepted criteria for the diagnosis of childhood autism. Boys outnumbered girls in ratio of 4:1. All had had at least one comprehensive evaluation at a reputable medical center. Their histories included reports from hundreds of skilled physicians and consultants. No child had a single diagnosis; some had eight: "He will grow out of it."; mental retardation; aphasia; childhood schizophrenia; chronic or minimal brain damage; chronic brain syndrome; symbiotic psychosis of childhood; and autism.

Similarities in histories, symptoms and signs of illness were shared by many children and pointed toward similar etiology: complications of pregnancy, early problems of difficult feeding, colic, milk intolerance, episodes of diarrhea and dehydration, onset of autistic symptoms soon after birth or during the second or third year coincident with the birth of a sibling or as the apparent sequal to acute febrile illness, first-born or first-born male, normal siblings in many families but a second neurologically impaired child in others (1:6), high incidence of twinning among siblings or members of immediate families. Multiple positive neurologic signs, unique slipping hand clasp, abnormal electroencephalograms (40-50%) seizures, stereotyped gestures, impaired hearing, visual defects (especially strabismus) left handedness or uncertain laterality (65%) and presence of concurrent organic disease (especially celiac disease).

Comments on Autism:

1. Severely affected autistic children have learned to read and write at an early age (under 5 years) without formal teaching.

2. Television plays an important role in the early acquisition of reading and writing skills, sometimes by a process of "lateral learning" during which the child is apparently indifferent to the broadcasts.

3. All autistic children can learn in an environment responsive to their levels of function.

4. Therapeutic intervention is most effective at an early age. It can be helpful at any age, however, whatever the severity of symptoms.

5. All autistic children are neurologically impaired (brain damaged).

6. All autistic children are functionally retarded in some measures [illegible] normal growth and development; some have precocious intellectual, artistic, musical or athletic abilities.

7. Comprehension is usually (?always) appropriate for age in spite of bizarre, abnormal or absent speech.

8. Significant delay is usual in response to verbal directions or requests for performance.

9. Treatment plans have tended to follow diagnostic labels rather than functional assessments.

10. Psychological tests, alone, are inappropriate and fallible guides to diagnosis, disposition and prognosis. Discrepancies between test results and performance are frequent.

11. Concurrent organic illnesses are often overlooked, untreated or mistreated. An association between celiac disease and autism is suspected.

12. Sensory defects (esp. visual and hearing) are overlooked, untreated or mistreated. When corrected, diagnosis may be altered and prognosis improved.

13. The use of drugs for the treatment of autistic children is chaotic and indiscriminate. Severe and frequent toxic reactions are unrecognized, unreported and untreated.

14. Individual psychotherapy has not been demonstrably effective.

15. Many autistic children are excluded from school although special education is the single most effective mode of therapy - in the light of present knowledge.

16. Autistic children are subject to abuse, isolation, deprivation and forcible restraint because of ignorance, oversight and neglect by society.

17. Potentially helpful insights of parents, teachers and non-professionals are frequently rejected by public and private agencies responsible for the care of autistic children.

18. Research efforts have tended to over-emphasize psychological factors while slighting clues to genetic, biochemical, physiological and environmental etiology (Notable exceptions are Rimland, Coleman, Osmond, Beaver, et al.).

19. Guidelines to effective educational therapy have been available for 160 years in the writings of Itard, Seguin, Montesorri, Piaget and Fenichel, but have been largely

disregarded in federal, state and local planning for autistic children.

20. Social and professional indifference towards the unmet needs of autistic children has encouraged the claims of charlatans and wasted the financial resources of parents.

21. Reliable studies of prognosis require long-term observations of children who have had access to optimum therapy.

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**Dr. Goodwin, and her husband, Dr. Campbell Goodwin, Chairman of our Professional Advisory Board, are among NSAC's oldest friends. Dr. Goodwin's observations grow out of more than twenty-five years of pediatric practise. Before her present position with the State of New York, she was Director of the Edison Responsive Environment Laboratory, Pediatric Department, Mary Imogene Bassett Hospital, Cooperstown, N.Y..**

**Special thanks are due to Normal Kreisman, Vice-President of the Responsive Environment Cooperation, for lending the machine which made Dr. Goodwin's workshop demonstration possible.**

Figure 1

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FIGURE 1a

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TYPING BY FIRST AUTISTIC CHILD TO USE THE ERE

FIGURE 2

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and it is the year 1964
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  room typing on the typewriter.

Paul is going to type a little story abo
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Last night I saw these shows on
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1234567891011213141516171819202122232425
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TYPING BY SECOND AUTISTIC CHILD TO USE THE ERE

# HOW THEY GROW UP---PROBLEMS OF MANAGEMENT, TRAINING, AND EDUCATION

Moderator: Eric Schopler, Director, Child Research Project, School of Medicine, University of North Carolina
Resource: Mrs. Nanette Doernberg, Director, Home Training Program, League School, Brooklyn
Mrs. Tomannie Walker, Chief, Social Work Services, League School, Brooklyn

## INTRODUCTORY REMARKS BY DR. SCHOPLER

It is a pleasure and a privilege for me to introduce these three panels on the management, training, and education of the different stages of the autistic child's development. It is especially exciting because the panels are composed of parents; it is the first time that a program of this sort has officially recognized that parents as well as professionals may have expert knowledge on as complex and elusive a condition as autism.

In my own work I am concerned with training parents to function as primary developmental agents with their own autistic child, so I am especially aware of parents contribution toward their child's development. My experience has given me cause to reflect on the relationship between what parents and professionals have to contribute toward the autistic child's welfare.

As professionals we see more autistic children than do most parents. We have a wider experience in the variations of problems experienced with these children. We have the opportunity to objectively compare, to speculate and to conduct research with groups of children, and thus apply procedures which have worked with similar children to a specific child.

Parents, on the other hand, are continuously involved with the same child. They have the opportunity to observe most closely their child's unique characteristics, abilities, and disabilities. Although many professionals are capable of empathy and understanding of the parents' plight, the stakes for parents are higher than for the professionals. Parents must evaluate and deploy their limited family resources and energies in terms of their total family.

They must consider the cost and payoff for special education or therapy for their autistic child against the cost and payoff of the education of their normal children. These are agonizing and difficult judgments. Though the professional may advise, only the parent bears the final responsibility.

From these considerations, I advocate that parents must become experts on their own autistic child. They have the most complete and relevant information available, from their daily life with the child. They have the highest motivation for helping their child and maintaining their family equilibrium. More community and professional help is becoming available, although for parents in many areas of this country the journey is still too often a lonely one.

Some may find the idea that parents should be experts on their child uncomfortable or far-fetched. However, the talent and energy represented at this meeting, the success your organizations have had over the four short years since your beginning, your contribution to improving the lot of autistic children, all reinforce this idea. It may be of interest that the appearance of this panel on this year's program has already exercised an influence on the professional community. Just before I left home, Dr. Ruttenberg of Philadelphia, who took part in last year's Annual Meeting, called me because he was setting up a similar panel for the meeting of the American Orthopsychiatric Association. This large professional organization has had workshops in autism at every meeting for years, but this is the first time they have included parents. In this country, parents have for too long been passively responsive to professional theories. It is high time that the interaction became more realistically equal.

**Dr. Schopler is Associate Professor and Director of Research Development, Child Psychiatry Unit, Department of Psychiatry of the University of North Carolina School of Medicine, and the author of many papers in journals of psychology and psychiatry.**

**Mrs. Doernberg and Mrs. Walker are co-authors (with Bernard Rosen) of A Home Training Program for Young Mentally Ill Children, published by the League School of Brooklyn.**

## PANEL I -- PARENTS OF CHILDREN UNDER 6

Dana Neimark, Silver Spring, Md.
Arthur Altro, Hartsdale, N.Y.
Joyce Leavitt, Albuquerque, N.M.

Mr. Altro, whose daughter is three, sketched a history of feeding problems, avoidance of eye contact, and other familiar symptoms. Consultations with doctors began very early, with the usual frustrations of an untestable child. At one and a half, it was "too early" to do anything; at two, according to another doctor, it was "too late". Mr. Altro watched the various autistic symptoms develop, recognizing them from the books he had read. He began to find reasons for his daughter's temper tantrums. These were typical of autism -- as when she screamed because a three-way light was turned to the wrong position.

Mrs. Leavitt's third child, Karin, had a diagnosis of autism by the time she was two, and hindsight shows that symptoms were present in infancy. She spun things, had ritual songs for recurring situations. Luckily, the Leavitts found early help as well as early diagnosis. Professionals -- including "a psychiatrist of the old school" -- were very supportive. Day treatment was begun three days a week, with speech therapy, operant conditioning, and high-intrusion therapy. Karin's present level, after one and a half years: some trained speech patterns, a very little spontaneous speech, extremely elliptic, with some comprehension of simple speech. She is toilet-trained. She is a happy child, and affectionate on her own terms. Her temper tantrums are less severe than when she was non-verbal.

Mrs. Neimark's son David at six, is an attractive child with an alert expression. His development to age three was apparently normal, although some remembered traits suggest disturbed behavior, notably screaming spells, occasional lack of responsiveness, and use of language almost exclusively to express wants and demands. By age four, however, he had regressed to a point where he rarely used speech and had stopped relating to peers or using toys appropriately. Increasingly, he "tuned out" his environment, and his night screaming had increased, sometimes to four or five hours a night. Exhaustive medical and psychological evaluations failed to find either physical or psychological reasons for his regression, but produced nine different labels before he was five, among them autism, childhood schizophrenia, and cerebral dysfunction. Today David almost never imitates speech, though he uses language when prompted and may answer questions. He responds affectionately to people who give him physical attention. He attends a well-known center for severely disturbed children. The screaming problem has grown somewhat less acute. His parents have tried many ways of handling it, including a three-week period of ignoring which they would not repeat, since although the screaming subsided, David grew more fearful and remote by day. Swinging him, taking him into bed, going into his room may help somewhat; a full-scale episode may be prevented if caught early.

Mrs. Leavitt: Karin has less extreme tantrums, but may be extremely irritable. She has a stock answer for "What's wrong?": "My nose is broken." Umpteen things are wrong, but none of them is what's really wrong. Should we ignore them?

Mrs. Walker: Ignoring can be hard on the other children, who feel that such behavior shouldn't be ignored. Diffuse discomfort is in a way harder to handle than specific trantrums.

Mrs. Doernberg: Would it have perhaps been better not to have switched treatment of the night screaming? It's hard to be sure what causes a personality change.

Mrs. Walker: It helps to have a cooperative MD who will prescribe medication.

Dr. Schopler: What about self-help?

Mrs. Doernberg: Watch for clues and go slowly. We're thimbleful people, along with Dr. Hewett. We work by tiny increments that must be programmed into us before we can teach them to our children. Any accomplishment strengthens both the child and the parent.

Mrs. Leavitt: We make her do motions, physically -- make her hands hold the cup, the spoon. You can withdraw gradually. You have to act differently than you do with your normal children; you have to become much firmer, more agressive -- intrusive. Don't hesitate to force the child to play ring-around-the-rosy.

Mrs. Walker: We have got the idea of leaving the child alone. Not these children -- instead we must intrude and push.

Suggestion from the audience: Try exercise, especially for sleeping problems. Hyperactivity is not exercise.

Mrs. Doernberg: Note the variety of solutions. Try anything -- except reinforcing the behavior by involving yourself in it, bouncing, rocking with the child.

**Mrs. Neimark is a former medical writer, head of NSAC's Library Committee, and Editor, Montgomery County NSAC Newsletter.**

**Mr. Altro is an engineer for WOR and President of the NSAC chapter in Hartsdale.**

**Mrs. Leavitt has taught Spanish at the University of New Mexico and in Sandia Girls' School, and is President of the New Mexico Chapter of NSAC.**

## PANEL II---PARENTS OF CHILDREN BETWEEN 8 AND 12

Vartan Eghigian, New Hartford, N.Y.
Clara Park, Williamstown, Mass.
Joyce Winters, Los Gatos, California

Mr. Eghigian described Jeannie, eight, the eldest of six children. Non-relating, essentially non-speaking, she is now in a public school, non-graded "adjustment" class. Mrs. Winters described Maywin, eldest of two, now eleven, as "a child who didn't cuddle, didn't respond to loving", a passive child. Great ingenuity was necessary to teach her simple social interactions, such as going out to meet her father on his return home. She went to school for the first time at six -- a nursery school for severely disturbed. The effort made to bring her into the community -- as in church and Sunday School -- has brought many embarrassing situations, but has led to much improvement.

Mrs. Doernberg and Mrs. Walker spoke of methods for establishing the prerequisite behavior for moving out into the community. Bus rides, which may be necessary for school, must be programmed step by step, making sure each step can be successful. Think it through in advance.

Mrs. Winters: She used to dawdle getting ready for school, and we knew she'd be terribly upset if she missed the bus. So to train her for the emergency, we had her miss the bus on purpose. We try in advance to prevent the establishment of a rigid routine.

Mrs. Park: My daughter Elly is almost twelve, the youngest of four children. Many of you have read about her in The Siege, which carries her up to age eight-and-a-half. She is making slow but steady progress in both speech and social adjustment, and now presents a curious combination of developmental stages. She has the social understanding of a not-very-perceptive three-year-old, with a three-year-old's cheerful response to people who take the right initiative (intrusion therapy again). Her speech is telegraphic, incomplete, and very labored, though her vocabulary is quite large. But her grasp of mathematical concepts is astonishing; she has spontaneously worked out the prime numbers from

1 to 1,000 and can give the prime factors of the remaining numbers. She is in a public school class for the emotionally disturbed, mornings only.

Audience question: How do you explain the child to others?
Mr. Eghigian: We don't explain. We pretend she's normal, expect the best and make a point of taking her with us when we go places.

Mrs. Park: We find we have to adjust to a new situation now that Elly is a big girl entering adolescence. In a way, it's easier, because she's made great progress, talks more spontaneously and intelligibly, responds more to experiences and people. But in a way, it's harder. Now, since she looks more like a teenager than a child we experience her behavior as more embarrassing -- "Oh, look! Baby in tummy!" We find we have to develop a new layer of toughness on top of the old ones, and parents of older children should be prepared for this.

Mrs. Doernberg: It's not possible to give generalized advice on how much to explain, and to whom. You parents are experts in autism, though, and you should realize that what you can tell people is a real contribution to educating a public that doesn't know very much about mentally ill children.

Audience Suggestion: Carry a supply of NSAC pamphlets or brochures of Dr. Rimland's Institute for Child Behavior Research. If the child has a tantrum in the supermarket or takes all the bottles out of the lady's basket, it's much easier if you can give these to the onlookers.

Mrs. Winters: Talking to people at this meeting has made me appreciate how lucky we are that Maywin is functioning so close to normal in so many areas. We find that many people simply don't believe she has had all the problems we say she has had. For instance, she's reading on a 7th-grade level now, when three years ago she wasn't communicating. She still has some problems, but she's doing much better than we ever dared to hope a few short years ago when we were told to put her in a state hospital and forget we ever had her. How glad we are that we didn't heed that advice!

Mr. Eghigian, an engineer, is President of the Cooperstown Chapter of NSAC, Vice-President of the New York State Chapters, and NSAC Educational Chairman.

Mrs. Park, a part-time teacher of English at Berkshire Community College, is an NSAC Board Member and Editor of the Newsletter. Her book The Siege (available through NSAC) describes in detail her child's development and the methods the family devised to help her. In 1968, it received a League School Citation and in 1969 a National Association for Mental Health Award.

Mrs. Winters is founder and first President of the NSAC Santa Clara County Chapter.

# PANEL III

## PARENTS OF YOUNG ADULTS 23-28

"I know what the words mean but not what the people mean."
-- Dick Dewey

Editor's Note:

**Panels I and II have been presented here in partial summary. Discussion presented in dialogue form has been reconstructed from notes, not tapes and is an approximation only. Because of the rarity of information on the adult development of autistic children, Panel III, a longer program, is given here not in summary but in the participants' own presentations.**

# PETER

by Frances Eberhardy, Madison, Wisconsin

Peter's autistic childhood needs no long description before this audience. He didn't cry much as a baby. He rarely laughed, and when he did, it was at things that didn't seem funny to us. He didn't cuddle, but sat upright in my lap even when I rocked him. His babbling had not turned into speech by the time he was three. He played repetitively, tearing paper into strips, spinning jar lids. On the rare occasions when I caught his eye, I would see his focus change from me to the reflection in my glasses. He did not speak his first words until three and a half -- after four months of work with the pre-lip-reading materials of the Tracy Course for deaf children.

He began to progress, although professionals later reproved me for trying to teach him, citing it as an instance of my intellectual approach to motherhood. He talked more, no longer repeating tonelessly what we said, but he had little spontaneous conversation, and what he had was often embarrassing. It was Dr. Leo Kanner who finally diagnosed him as autistic, and added that an autistic child who talked as early as Peter did, might, if he got enough help, be able to live a normal life. He recommended the Woods Schools, in Langhorne, Pa., 1,000 miles from our home, and in nine years of patient (and expensive) education there, Peter progressed to the point where he could take high school equivalency exams and think about the future.

He had always wanted to tune pianos. When he could barely reach the keys, he would spend minutes playing one note and swaying from foot to foot like a metronome. Later, when he was in the spinning period, he shaped his can covers with a little hammer. My husband thought he was tuning them, but I didn't believe it.

When Peter was sixteen and still planning to be a piano tuner, we realized he was serious. We asked advice from the man who tuned our piano. He helped us order the basic tuning tools, gave Peter a little instruction and told us to get him an old piano. He said he would check it when Peter was satisfied with its pitch. Some weeks later, when the tuner checked Peter's piano, he told us in amazement that Peter could tune a piano as well as he could.

This scarcely seemed like enough training to us. We learned that a correspondence course was available which gave practical information on making repairs, as well as the theory and technique of tuning. Peter studied this along with his academic work at the Woods Schools. The following year, his last, he spent in a vocational program, learning how to handle tools, materials and most important, job responsibility. The school had a large supply of old pianos in constant need of repair.

During his holidays, Peter had tuned pianos of our friends, so that when he came home permanently he had already had lots of experience. To prepare him to meet the public, I set up playlets, demonstrating how different housewives might act, and how they would expect him to act. I tried to imagine all the problems that would come up and give him forms for handling them: where to put his coat, how to give his estimate of the cost of repairs, how to write up his bill and present it, and a lot more.

At first, Peter needed a great deal of help. We have been able to withdraw most of it as he has become more capable. I still make his appointments and some one of the family drives him to and from his jobs. Peter doesn't have the ability to make quick decisions necessary for driving in traffic, and he realizes it.

Three or four days a week he works in stores where he can leave a supply of tools, so there is less driving than there was at first. Some day, Peter may do just store work. But he enjoys the social contacts that home jobs give him and the praise that often comes his way. For the present, we will continue to drive him so that he can get into homes.

We helped Peter set up a bookkeeping system and now he handles this himself. At first, we helped him order his supplies and make out his tax forms, but now he is able to do these himself too.

Socially, Peter reminds me of the

Young man so benighted,
Who didn't know when he was slighted.
He went to a party,
And ate just as hearty,
As though he'd been duly invited.

Peter just doesn't understand---oh so many things. Why he shouldn't stand so close, how to introduce his favorite topics into a general conversation. He senses that there is something funny in a joke, but we have to explain what the same word means in different contexts. And then we explain again.

He is interested in politics. He postponed his supper one night so he could go to a hearing with us. He reads the newspaper from front to back. I gave up my subscription to a newsmagazine because he was getting frantic since he couldn't keep up with all the reading. He identifies with the underdog. He is very conscious of the wrongs done to the Negroes. He donated generously to the earthquake victims in Peru.

Peter pays us for room, board and transportation. He is conscientious about it, but expects me to pay for half of it when I do errands on the way. I tell this, not so much as a joke, but for reassurance, since I once had worried that Peter might be a likely victim for a confidence man or woman.

Peter has made continuous progress since he returned from Woods. Friends who seem him only occasionally remark about his greater ease with people. He has no real personal friends, but has achieved a good relationship with his employers. He does not seem to suffer from his differences from others. It is many years ago that he asked me, "What's wrong with me? I feel like a freak." The label "emotionally disturbed" seemed to reassure him that there was a reason for his peculiarities, and success in his job has steadily bolstered his self-conficence. He tells us that he does not plan to marry; his interest in girls is slight, and he doesn't think he'd be able to raise children.

Of course, we are concerned about the future. We have a daughter who can help him get situated, probably with the help of some social agency, when we are no longer in the picture. We have tried to give him a little domestic training so he could manage in a small apartment. We think he might be better off with a family, because he likes people, but doesn't know how to develop friendships on his own.

Many people have helped Peter and they all deserve credit. But Peter has put out the most effort. And the potential must have been in him to make his present accomplishments possible. It is hard, even for me, when I see Peter carrying a forty pound case of tools to realize that he is the little boy whose hands were so weak he couldn't pull on his own rubbers.

**Peter's early history is given in more detail in Mrs. Eberhardy's "The View from the Couch", Journal of Child Psychology and Psychiatry, Vol. 8, 1967, pp. 257-263. Copies are available from NSAC Information and Referral Service, 121 Richmond Street, Huntington, West Virginia 25702. Mrs. Eberhardy is a registered nurse, and it was this work that enabled the family to meet the heavy costs of Peter's education.**

# DICK

by Margaret Dewey, Ann Arbor, Michigan

Dick was the third of our four children. From birth, he responded differently to people and to sound. He clearly showed all symptoms described by Kanner, but neither we nor our pediatrician recognized them 22 years ago, and we sadly accepted the diagnosis that he was mildly retarded before he was three. The doctor told us to love him as he was, that he might get to eighth grade in special classes, if we were fortunate.

We delayed school until Dick was almost six. Although he tested as having an I.Q. of 82, the principal started him in regular classes because we had taught him to read at home while trying to help him learn how to talk more usefully. Dick stuck with this class through high school, - where he was affectionately regarded as both a nut and a genius. He continued into his second year of college before he felt overwhelmed and dropped out. This is a great simplification. I have never seen anyone work so hard to do well. And he tells us now that he was miserable in school. He won his college admission because of good grades and excptional musical ability, in spite of low college-board scores. He composed freely in high school and did extremely well in his college composition course, but became discouraged at his failure to understand the randomness and lack of order of modern music (e.g. John Cage). It was at this time that he decided to become a piano tuner -- an idea he had not mentioned since he was five. Dick may yet realize his ambition of becoming a composer, but he is realistic about his chances of making a living this way. He is now a piano technician, whose meticulous tuning is sought by professional musicians.

Dick started talking by echoing what we said. His pronouns thus came out reversed, and he was unable to answer yes-or-no questions. Original speech began when he was about four; though he still echoed for a time. His father, a language teacher, drew up paradigms of verbs for him, as if English were a foreign language. Today, he speaks in a loud voice with a large vocabulary. He prefers a long word with a single meaning to small words which change unaccountably in different contexts ("procrastinate" rather than "put off"). Non-verbal communication still puzzles him, and departures from literal meaning, as in irony, bewilder him.

Dick first heard the word "autism" when he was 18, and seemed happy to know what his problem was. "I am glad it is a real thing, rather than my fault for not trying hard enough." Before that, he told people he was retarded -- that he fell out of a moving car when he was three. He gladly gave me permission to talk about him at this conference. When I first told him I had been invited to participate, he smiled and said, "I have done something nice for you, haven't I?" This suggested the following essay, which Dick says is 100 percent correct. He has never before given such an endoresement to my attempts to understand his feelings.

As your autistic child grows older, he may be as sensitive to hints that he has been a special burden as you are to hints that your personality contributed to his problem. He is aware that he is somehow different without understanding the labels and theories which have been applied to him. Some of the literature about these children stresses that they cause hardship for their families; socially, financially and emotionally. It is possible that your child will someday read this, and feel defensive and guilty, just as we felt the first time we read the dubious theory that babies become autistic by turning away from hostile parents. We deny this with all the inner knowledge of our hearts, yet we feel guilty about any aspects of our imperfect personalities which could be interpreted as rejecting.

The truth is, our child did not ask us to make sacrifices for him. He, too, is a victim of something not yet understood. He suffers from it, and in many cases makes a heroic effort to compensate. When he tries his hardest, he gets little credit, because that is when he seems most normal. But if he gives in to despair and expresses his frustration, the tempest is held against him by people who have little understanding of the depths of his misery.

The literature describes him as withdrawn and unsociable, but his attempts at sociability are poorly rewarded. Because he is as handicapped in the nuances of social intercourse as he is in language skills, his efforts are often awkward and inappropriate. He may show friendly interest by asking questions which are too personal. He may try to be responsive by giving elaborately detailed answers to casual inquiries. If he expresses his tender emotions by standing too close to a pretty girl or by stroking the soft hair of a baby, people move away uneasily. In extreme instances they may even call the police because he failed to observe the social difference between friends of his family and total strangers.

All of this is just a glimpse of the humiliation an autistic adolescent suffers. We can begin to appreciate it if we recall our own feelings of inadequacy at that age, and multiply them a hundred times. He has every right to feel defensive at the suggestion that he "made" a problem for his family. He merely shares his handicap with them because he happened to be born to them. This is a matter for mutual sympathy and understanding in which we, as parents, must not seek the rewards of martyrdom.

Since I wrote this, Dick has been making an effort to correct what we call "social echolalia". He is studying the social equivalent of grammar, aware that behavior, like pronouns, should be changed for gender, person, and time. We hope, however, that he keeps his admirable social tolerance. He calls anyone who is nice to him "my friend", whether that person is sixty or six, regardless of race, class, or education.

Dick likes girls, but until recently he has been disappointed in their response. He has made friends with some foreign girls who appreciate his musical talent. His pedantic language and social awkwardness are less obvious to them. This year, for the first time, some American girls have been friendly to him. Much is changing among our young people, and the new social values of today's restless generation work to the advantage of all autistic children. Eccentricity is now tolerated, individuality is admired, and the guileless person is called beautiful.

Appearance is unimportant. (We can expect that the grown autistic child will forget to have his hair cut, and be unaware of style changes.) The single person is no longer a social misfit. (Few autistic children grow pliant enough for marriage.) But craftsmen and workers are admired if they do their thing well, however humble -- and no more conscientious worker exists than the autistic child who has found his place.

**Mrs. Dewey who taught English composition at the University of Michigan before Dick's birth, has recently returned to graduate study in special education, social work, and psychology, but finds that her "most valuable research is done in the medical library". Excerpts from her accounts of Dick have been published in the NSAC Newsletter, December 1969 and February 1970.**

# PAUL

by Harriet Mandelbaum, Brooklyn, N.Y.

A detailed account of Paul's early development is unnecessary here. I need only say that his was a classic case of childhood autism, diagnosed as early as age three, with a very bleak prognosis. Hospitalization was recommended with a prediction of lifelong institutionalization. This future without hope was presented to us again by another psychiatrist when Paul was five, this time with the additional detail that he would never read or write. "Realistic" as this advice might seem in the light of severe handicap, we refused to give up our son without trying. Now at 28, he is working at a job he has held for nine years in the shipping department of a chemical company - in the real world.

Yet the professionals were certainly right at that time in the light of what they knew and of what alternatives were available. I think, in part, their verdict was unacceptable because as a teacher I had a stubborn faith in the power of the educational process for every child. And so we started on the familiar rounds of the search for a school. It was obviously not a matter of choosing a school, but of finding one willing to accept him. The possibilities were limited, but we tried them all.

First, we found a nursery school for normal children with a sympathetic director and a teacher willing to try. It was necessary for me to stand by much of the time, and even an understanding teacher could not be expected to provide the necessary individual attention in a class of fifteen. For me, however, there was poignant gratification simply in seeing him seated in a circle with other children and clapping his hands in rhythm along with them. It soon became obvious that the school could do little more than tolerate him and we resumed our search. After another such attempt which started hopefully, he went into a severe regression, losing what limited speech he had and developing uncontrollable anxieties. It was necessary to hospitalize him for a short period.

The next possibility was finding a school primarily for retarded children - but one with a structured learning program. We found this in a residential school not far from home where - as was always to be the case - he was accepted on probation. After a difficult trial period, he adjusted to the routine, was placed in a small class where he responded to the teacher's expectation and patient demands and slowly began learning the rudiments of reading and writing. In addition to the value of an educational program geared to his needs, the school taught us the importance of learning the social amenities. Paul was taught the language and ritual of etiquette and even if he learned it mechanically at first, I am sure that the positive response it elicited from others helped him to establish contact at a time when he was very withdrawn. It was much easier to take him to restaurants, for example, and on his home visits he was less anxious and more responsive. To this day his good manners, now much less mechanically applied, help him gain acceptance and approval at work and in social contacts.

At age ten, his slow progress leveled off to a plateau and it became apparent that another school was indicated, still sheltered, but perhaps more challenging and with a wider variety of learning areas. We decided to try another kind of special school. We found one primarily for disturbed boys with severe behavior problems - anti-social, acting out, delinquent - many of them court-referred. It was close enough to home for frequent visits, there were spacious grounds, a working farm, small cottage units, and a good school. We had to face the risk of placing a strange withdrawn ten year old among boys who might make him a butt. However, the alternative was nothing. The school was willing to try, with the possibility of starting a small unit for autistic and schizophrenic children if it worked. After the usual period of holding our breath - after a difficult adjustment period during which Paul seemed more withdrawn - we knew it was working. Instead of making him a target for teasing, the boys took a protective attitude, even taking pride in his progress. I remember one of our early visits when we were greeted by one of the boys in his cottage with, "Hey, Paul's talking a lot more. Wait till you see!" He might not have made it without those earlier years at the Woods School where he learned self-management, simple classroom routing, and the reassurance of a predictable schedule. Here with the help of warm house parents, he did his share of household chores, cared for his clothing and room - and today he is by far the neatest member of our family.

At 16, he reached the age limit at Hawthorne. The next step involved finding a facility for a difficult in-between age as well as one which might provide vocational training. Vocational aptitude tests at Hawthorne had suggested possible training in horticulture or office skills and the school had started him on typing with some success. The only school we were able to find was a residential training school for retarded teen-agers and young adults. The vocational training consisted of contract work for small manufacturers with no regard for individual abilities and for a long period Paul spent his time removing paper from shoe soles. We still had no idea of what he might really be capable of, but we felt we had to try something beyond this before he risked losing the gains he'd made at school.

At this point, we decided that whatever we attempted would be done with home as his base. At 17, he came home to stay and I began making the rounds again. I looked into training units for a wide range of handicaps, but none was willing to accept him because "he wouldn't fit into the program". I finally went to the state Division of Vocational Rehabilitation where I learned that their programs were primarily for the physically handicapped with some new provisions for the retarded. I had the good fortune to be assigned to a social worker aware of the need for programs for the mentally ill, who arranged for the D.V.R. to sponsor Paul in a business school. He found one in Brooklyn with a director who seemed to specialize in problem students and Paul was enrolled in a small class for typing and filing. The repetitive and ordered nature of these skills was well-suited both to his abilities and limitations, and in addition to continuing progress in typing, he demonstrated great accuracy in spelling and filing.

At the point where D.V.R. felt he was ready to try employment, we knew he had mastered the skills, but we had some misgivings about the possibility of his getting along in a setting that might involve pressures, social problems and the need for judgment. We put his office skills to the test for a while by arranging to have him work as a volunteer at the office of the National Organization for Mentally Ill Children, again, of course, with accepting, understanding people. However, he demonstrated ability to follow directions and do assigned jobs and the D.V.R. decided to try to place him in a paying job. He was given some preparation in coping with job interviews and filling out applications and finally was hired by a drug concern as a shipping clerk. The first weeks were difficult: some of his old anxiety returned, his speech became repetitive again and he asked questions about his work over and over and then repeated the instructions to himself. The employer was patient and must have seen his potential for productive work through some of the strange behavior. After a while, Paul became comfortable with the routine, was much more relaxed and his employer told us some years later that he was worth any two men in his employ. The remarkable memory which so many autistic children have, stood him in good stead: people could ask him the number and date of any shipment and get the answer without consulting the files. He finds great satisfaction in completing a job and is not easily distracted - the same quality, perhaps, which kept him piling up blocks until every one was used or sitting at a puzzle until it was finished. Although he is liked and appreciated by his co-workers (his birthday is announced on the loudspeaker and he always comes home with gifts and personal notes at this time and at Christmas), it was obvious that his job could not be the source of his social life. This has been provided by the Young Adult Institute, a facility which provides employment preparation and social activities for mentally handicapped young people. Paul is a member of the Alumni Club, a group already employed and able to make independent social arrangements in addition to planned activities like trips and current events discussions. He makes dates to go bowling, visit museums and zoos, or just walk. Unlike Dick and Peter, Paul has not seemed conscious of his difference from others. We did not wish to create a sense of difference by talking about it, and he never asked. He did once ask why he didn't "walk to school like Myra," and was satisfied when told, "You wouldn't be happy in your sister's school." (Of course, he may simply have been asking about transportation.)

We've been lucky, of course - but it hasn't been as simple as a necessarily telescoped account might seem. There was the steady progress, but many times along the way there seemed to be only closed doors and dead ends. It's hard to convey our anguish at such times when we felt that whatever he had gained might be lost because there was no place to go from there. We'd have settled for a plateau, I think, almost anywhere in the last nine years, but he continues to make progress. What has struck us all along, much more than our being able to find (and finance!) the facilities, was the effort that Paul was able to put into using every opportunity provided. Not that he is "normal" now. His speech, although much more a means of communication, is still rather deliberate. He shows more curiosity about the meaning of words and asks more questions, but his reading is entirely factual - sports, geography, etc.. (He has always had a keen geographical sense and on the night of the blackout was able to find his way home by taking a series of buses and walking, instead of his fairly direct one-hour subway trip.) He cannot, however, understand novels or the continuity of movies or television plays. He recounts them as almost unrelated parts. However, as a result of simple discussions, he has some understanding of politics and votes, I suppose, as intelligently (if not more so) as large numbers of citizens. He's very responsive to praise and we have tried more and more to teach him new skills which in the past might have seemed beyond his capacity: he uses a power mower, plays anagrams and croquet, helps operate a sailboat, etc.. He has become much less rigid about scheduled tasks, which he used to feel had to be done at the same time, in the same intervals. He volunteers, for instance, "Can the grass wait?" yet still always carries out his responsibilities. He's up in the morning long before the rest of the family, makes his own breakfast, clears, and is always on time at work.

Since he was the oldest child, his illness created problems for younger siblings (which might be the subject of another paper). During his periods of severe anxiety and screaming, their routine was constantly upset. They have, however, remained very close to him and our visits to school when he was away turned into pleasant occasions, involving picnics and exploration. Now his sister, brother and (brother-in-law) are very proud of him and consider him the happiest member of our family.

We cannot now anticipate a future of completely independent living for him and the problem which faces any older parent of grown-up autistic children is still unsolved: what happens after we're gone? Will it become his sister and brother's responsibility? There is at least hope now that he will not be an economic burden, but we shall have to consider the possibility of a supervised residence at some time - perhaps like the hostels New York State has started for employed retarded adults.

It's risky to base conclusions on a single experience, but I have seen enough mentally ill children develop into productive adults to know that society is criminally negligent in not providing the opportunities. Paul's story simply proves that hopeless prophecies are indeed self-fulfilling, if schools and training are not provided and that the stubborn quixotic hopes of parents are not unreasonable.

It's important to remember as we see the common and familiar symptoms of autism that the children are individuals with a wide range of personality and intellectual differences. Whatever program we plan must take into account not only the handicap, but individual needs and talents. After Paul's anxiety and tensions disappeared in a controlled reassuring setting, he revealed a sweet, generous nature.

Our own attitudes will be conveyed not only to our children, but to others. If we're apologetic and embarrassed, we'll reinforce the fearful attitudes of neighbors and strangers.

I have continued to be surprised to learn how much Paul heard and absorbed when he seemed to be out of contact. Even now, at times when he seems lost in his own thoughts, he'll respond to a joke (he has a hearty spontaneous laugh), or ask the meaning of a word, or refer to a conversation overheard long ago.

Long term planning is not practical -- each step and each achievement determines the next need. It is difficult to predict how long any particular setting will be useful and the lack of the necessary range of facilities makes improvising and agressiveness necessary; pushing the local school authorities, badgering community agencies, organizing programs at home - even starting projects ourselves.

There's enough evidence now to know that the risks are worth taking. I know autistic children who have grown up to become messengers, file clerks, watchmakers, busboys, post office employees and other civil service workers. Others have not made it to vocational independence, but every step along the process of trying has helped in some way, and the only way to find out how far any child can go is to try.

Our reach may well exceed our grasp - but we must never stop reaching.

# MY EXPERIENCES AS AN AUTISTIC CHILD

William J. Donovan, Jr.

Introductory Remarks by Mrs. Donovan:

Bill was different from the beginning, and not only because congenital cataracts allowed him extremely poor vision. He never liked to be held or cuddled. As he grew older, he became hyperactive. He broke four playpens jumping and jumped out of his crib twice. When he started to talk he only spoke in rote. He repeated every television commercial he heard and everything that was said to him. He acquired normal speech patterns about 9 or 10. He was terribly destructive and had to be watched all the time. When he started going to public school, he was able to go for 20 minutes a day. The teachers were totally unaware what was wrong with him and had a very difficult time controlling him.

The biggest problem that these children have is fear. Every new situation is a threat. We felt that by constant exposure to new situations, we would lessen the fear and after a long time this is what happened. After some painful experiences with the public which we ignored completely, Bill started to become socially acceptable.

He was always aware of what people were saying about him. We never knew how Bill felt until he was much older and able to tell us all the things that happened to him along the way. We tried to give him a feeling of security. It helped that he was the youngest. Since there was an eleven-year span between him and his two brothers, he was like an only child and didn't have to share us with younger children.

Bill was illiterate until the age of 11. He was not able to learn before that because fear got in the way. When Bill was young, little was known about autism and parents were so grateful to have their child accepted in school that they overlooked the bad things. Many of the teachers were not able to cope with him and things were done that were dreadfully wrong. Nevertheless, going to school every day is very, very important. I would like to stress this point. Even though Bill disliked it intensely, it helped to structure his environment and helped his adjustment.

Of course, we consulted many people, but we were paying professionals for advice they didn't have to give us. We paid fifty dollars for a twenty-minute visit and were told to put Bill in Bellevue; there was nothing that could be done. Five years ago, we were told that Bill could never hold a job. We proved that wrong.

Never be embarrassed about taking them places. When Judy Garland was playing in New York, we decided to get a box seat and take Bill to see her in person because he loved her records. God bless Judy, she was wonderful. Bill was directly over her head and acting up as I expected he would and she looked up and said, "What's the matter, darling?" That little bit of recognition from her made all the difference. He calmed down and enjoyed the rest of the show.

The whole family shares in Bill's progress. Realizing that he needed attention most, they all contributed ungrudgingly. It has been a difficult but rewarding 21 years for us.

At this point, I would like to introduce my son Bill.

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As an autistic child, I felt very uncomfortable. The hardest thing to accept was not being able to talk. I tore up newspapers, pulled bedspreads off the beds, pulled books out of the bookcases, bounced cans and played with spinning tops and broke every one of them. I would like to take this opportunity to tell you I destroyed things and this is because I couldn't talk. I spun things because I couldn't talk. It also made me feel good, of course.

I hated going to school because classrooms were too confining. I didn't like the idea of the other kids making fun of me and I didn't want anyone to pass judgment on me as to how good or bad I was. I resented the teachers discussing me as if I didn't exist. I didn't like the bus drivers complaining about how I behaved in the bus. What I hated about school most and got upset over were marks, tests, grades, homework and written work. If they did away with marks, tests, grades, homework and written work I would have enjoyed school better. I found the classroom too confining and the other kids made fun of me. I hated being with the other kids. I found it very difficult because I couldn't talk or communicate to anyone. It was very hard to accept. Name calling was too much for me. It was then that I began to realize that I was different.

Fear was my biggest problem. It was a terrible feeling - it was a terrible feeling. It was very hard for me to communicate so I screamed a lot because it helped my frustration and cleared the air.

One teacher smacked everyone on the seat of the pants with a ruler and threatened me because I left crumbs on the desk. One teacher locked me in the closet and smacked everyone's hand. This made me hate school all the more.

My parents worked very hard with me to make me socially acceptable. They gave me a lot of tender, loving care. They took me everywhere and gradually my fears lessened. Once I started to talk, I began to feel better.

I now work eight hours a day for a packaging firm and I enjoy my job very much. The happiest day of my life was the day I went to work. What I like best is being with kind people.

Question: Do you have a tape recorder?

Answer: Yes. Richard (his brother) gives me tapes of Charlie Brown. I think Charlie Brown is very interesting.

Question: When did you learn to talk?

Answer: I learned to talk at 4. I didn't learn to communicate until 11 or 12.

Question: Was it because you couldn't talk or wouldn't?

Answer: (With great emphasis) Couldn't.

Question: Were you afraid of large crowds?

Answer: No, I was only afraid of teachers who would threaten and punish.

Question: Did you try to communicate?

Answer: Yes, I tried to.

Question: What helped you most?

Answer: Some job training. Not marks, tests, grades, homework and written work. The school for the blind was better.

Question: Were you afraid of other children?

Answer: No.

Question: But you still didn't want to play with them.

Answer: Exactly.

Question: Did you get anything out of going to school?

Answer: Even though I didn't like going to school, I think it helped me. I think children need to be kept busy. I think what I resented about school was I didn't get lots of attention like I did at home.

Question: Have you any plans on what you'd like to do with your life?

Answer: Yes, I'd like to take care of dogs.

Question: What would have been the best way to handle you when you screamed?

Answer: He screams because of something within him. I don't think anyone knows why.

Question: What were some of the methods of teaching?

Answer: They did hit me quite a lot when I didn't pay attention.

Question: Did that help you?

Answer: Not exactly.

Question: Did it help you pay attention?

Answer: Yes.

Question: Have you any hobbies?

Answer: Yes, I wash and wax cars and I like that because it keeps me busy, and I taught myself to play the accordion. I belong to the Young Adult Club and we go on trips.

I feel wonderful here today. I feel like the President. I hope all autistic children could grow up to be socially acceptable.

**Bill went briefly to nursery school, then for several years attended a public school class for the emotionally disturbed. He then moved to the Lavelle School for the Blind in New York. There the children were more accepting of him and his behavior and the special attention of an interested teacher allowed him to make up work that he had missed in public school. Surgery on his cataracts has had little effect.**

## FEDERAL RESOURCES

Participants: Herbert L. Rooney, Chief
Citizen Participation Branch
National Institute of Mental Health

James R. Tompkins, Coordinator
Unit on the Education of the Emotionally Disturbed, Office of Education

United States Department of Health, Education, and Welfare

In an informal workshop presentation, Mr. Rooney encouraged parents to become knowledgeable about program officials and elected officials at local, state, and national levels in order to make their needs known. The complexity of service demands on elected officials makes it impossible for them to know the various needs of everyone, but they will listen and often respond when they are informed of genuine needs by groups of citizens. (Mr. Rooney's support, which alone made possible the publication of these Proceedings, is itself a striking example of the imaginative use of federal resources.)

Mr. Tompkins surveyed existing possibilities of federal help. A condensation of his remarks follows:

The Bureau of Education for the Handicapped, one of seven operating bureaus in the Office of Education, provides a voice at a high policy level for the interests of a variety of specific minority groups. The Congress and the Executive Branch, during the last decade, have produced a wide variety of legislative authorities to advance educational opportunities for the handicapped. With the establishment of a Bureau of Education for the Handicapped, we now have over 100 people working in the area of the handicapped, instead of the handful available only a few years ago. We now provide support for educational research directly related to the needs of handicapped children. Among other projects, we sponsor Instructional Materials Centers throughout the nation to distribute material and media to teachers. P.L. 85-926, as amended, extends support for undergraduate and graduate training programs to 75 colleges and universities to provide qualified personnel to work with emotionally handicapped children. Title VI-A of the Elementary and Secondary Education Act, P.L. 89-313, allows state and state-supported institutions for the handicapped to receive help for their educational programs. Media services and captioned films provide special instructional materials to the classroom teacher or therapist for all categories of handicapped children. Regional Resource Centers provide consultant assistance to special education teachers. Centers for Deaf-Blind Children give educational assistance to the multiply-handicapped. Research and training programs in physical education and recreation for retarded and other handicapped children are supported, along with an information and recruitment program for parents and teachers of the handicapped. The Early Childhood Education Act, when fully funded, will provide for 70 to 100 demonstration centers for early education for handicapped preschool children.

In addition to the programs administered directly in the Bureau of Education for the Handicapped, there are four other programs which are of great interest.

First, Congress has required that at least 15% of Title III of ESEA dealing with supplementary centers and innovative programs be spent on projects involving handicapped children.

Second, the new Vocational Education Act has several provisions for including the handicapped, notably 10% of the funds for a State plan program that must be spent on handicapped children and youth.

Third, the new Higher Education Act has provisions for special programs and services for physically handicapped college students.

Fourth, an agreement made with the Bureau of Educational Personnel Development provides that 15% of their training funds will be spent on the handicapped. These funds will be particularly useful in helping regular education personnel learn about the handicapped and in training professional aides.

A leader in special education offers this example of our national priorities. "Many of us frequently travel on one of the many fine beltways around our major cities -- an important part of a modern transportation system. Every time, however, that your car clicks off a mile on that beltway system, you should realize that the cost of constructing that mile was about $9 million. If you traveled completely around the beltway of any major city, the cost of that section of road surpasses the total Federal Budget for all aspects of education for handicapped children for either fiscal year 1969 or 1970." Yet money is always available for programs that society values, or finds entertaining, or for programs that reduce a feeling of guilt. If we do not have money, it is because people have not perceived our area as a high priority one.

In the past, educators have often functioned as if they believed the virtues of their program were self-evident. They believed that if they were good a school board, or a superintendent, or a federal agency would provide financial assistance. Resources will accrue to special education, however, not just on the basis of manifest value, but only when there is a greater understanding of how political decisions are made.

**Mr. Tompkins brings to government administration a wide experience in the therapy and teaching of the severely disturbed child. He is the author of several articles on special education.**

**Mr. Tompkins has been with the Bureau of the Handicapped for the past five years. He is currently Vice-Chairman of the NIMH Bureau of the Handicapped Joint Planning Committee for Children's Services (Child Advocacy). Prior to his present position, Mr. Tompkins was Assistant Principal and Crisis Teacher at Hillcrest Children's Center, Washington, D.C..**

# HOW TO WORK WITH YOUR STATE LEGISLATURE

S. Clarence Griffith
Founder, Georgia Society for Autistic Children
Christine Griffith
Chairman, Georgia Society Legislative Committee

In 1967 autistic and other behaviorally disordered children had no educational facilities in the state of Georgia. Seeking help alone for one child we found nothing. It was apparent a group effort must be made and we formed our Chapter. A little more than one year later, we had a pilot project in DeKalb County for autistic children financed by the state and under the direction of the local school board. The Woman's Club in Sandy Springs, an Atlanta suburb, now has a pre-school program for autistic children. The First Baptist Church in Decatur, another suburb, has for the past year helped the Georgia Society sponsor a research project for pre-school autistic children and has successfully integrated them into classes with normal kindergarten children. As of September 1970, Georgia has three centers for autistic children: in Athens, Savannah, and DeKalb. Georgia now has an Exceptional Child Law, passed in 1968, and the current state education budget specifies "autistic" in mandating educational facilities. Autism is a household word in Georgia. Here are the methods we used to accomplish this.

1. Contact the League of Women Voters. They have an education committee and can give you most information you will need. The Georgia League for years has supported facilities in all areas of exceptionality. Ask them to help.

2. Go to your local school officials (special education department) and find out exactly where our children are being served; then go to your local school board. Don't attempt to tell them what to do or make lengthy statements; simply state the areas where the needs of the children are not being met. Let them determine how to meet those needs.

3. Contact the Federation of Women's Clubs in your state.

The state office is usually found in the capital city, but any local club can give you information and help. These groups have Youth and Family Life, Mental Health, and Education Committees and the state chairmen will welcome your inquiry and give you help.

4. The Jaycees in Georgia have mental health as an area of their concern. Contact and ask them for help.

5. From these three organizations some concrete suggestions will come. One thing to solicit from them: have their state committee chairmen on mental health or children make appointments to accompany the committee chairman from the Society for Autistic Children to visit the state special education department head, the mental health department, state school superintendent, and the governor.

6. When you have done all these things you will have enough information to escalate your campaign.

7. Your Public Relations Committee should constantly monitor TV, radio, newspapers, PTAs, church bulletins, or any place where autism can be brought in. Your chairman will have to be deeply dedicated to the cause to be effective, and it will be best if he or she is not professional.

8. Your biggest job is to educate the public (elected officials are part of the public). During one week we sponsored a music therapy workshop and had the Protestant TV hour at 6:30 Sunday morning, with two mothers and an autistic child who was an excellent example of how a child can improve. We sent an invitation to the governor and every member of the legislature to come to the workshop (at a local hotel) and to watch the TV show. When House Bill 453 "Exceptional Child" was being debated in the Georgia House, a member moved to delete dyslexia and autism. Another member rose and stated, "'Autistic' is a label that has been used in the past to deny a child an education; I want it used once for an autistic child." This member had attended our music therapy session. Dyslexia was dropped but autism was put back into the bill.

9. The Secretary of State has a booklet giving information on all committees in your legislature. You should be concerned with Education, Mental Health, and Institutions' committees. To get a personal relationship going with these chairmen is essential, as well as with the members of the press.

10. Get to know the people elected to represent you. Call them and state your problem with your child. Ask them to obtain for you copies of the laws in your state governing programs and facilities for handicapped children. Regardless of how much you already know about your laws, the object here is to educate your representative and make him do something for you. For the same reason, when you are seeking information from Health, Education, and Welfare or the Department of Education of the Federal Government, submit your request through your elected representative rather than directly to the department. You can be sure the word "autism" is not in your laws. Read them and find places where they should be changed.

11. The mental health laws in Georgia are constantly under review; in almost every legislative session bills are presented affecting mental health. The chairman of the mental health committee in Georgia, Senator Bobby Rowan, is the best friend our children ever had. Public hearings had been scheduled on our Bill of Rights for the Mentally Ill (now become law) and we attended all the sessions, opening our mouths almost constantly, pointing out flaws in what health department employees were saying, and in general being obnoxious. In spite of all this, Senator Rowan was glad to meet us and have our comments and stated, "These parents are trying to help their children. They are not here begging me for a place to commit their children, they want to help themselves."

12. Attend all functions involving candidates seeking office. We try to have three people who will stand and ask questions at public rallies, etc.. We have one very popular radio station and we get autism on it at least once a week.

13. In brief:

   A. Form or join a group and approach the legislature on a group basis.

   B. Get to know your representative and the key representatives in your legislature.

   C. Get acquainted personally with the press and publicize what you are doing and what you are trying to do.

Mr. Griffith spoke as President of the Georgia Society and President-Elect, (now President) of NSAC. He is Administrator of the Ponce de Leon Infirmary, a private hospital in Atlanta. His wife Christine, fortified by her years in the League of Women Voters, is his able co-worker.

# SCHOOL IS FOR ALL CHILDREN

Edna Koehler
Director, Special Education
Henry C. Hall School, Marin County, California

Ernest F. Giraldi, Jr., M.D.
Resident Psychiatrist
Letterman General Hospital, San Francisco, California

A public school program for autistic children, located on the grounds of an elementary school in Larkspur, California, has shown that significant progress is possible even with severe cases. Using a definition of autism as "a disorder of communication," the program developed by Mrs. Koehler and Dr. Giraldi offers "a bombardment of stimulation" with a variety of stimuli. A one-to-one ratio is maintained by the imaginative use of volunteers, including college students and children from the adjacent school, who assist in classroom and playground socialization. Both teachers and volunteers make use of reinforcement techniques, using positive reinforcement only. Mrs. Koehler does not select the easy cases. "I take anyone in the beginning. I don't even look at their records, I just see what I can do with them." She maintains that the autistic child can and should be educated in the public schools, and the program includes children who would otherwise be slated for institutionalization.

The children are integrated into as many normal situations as possible, spending time in normal classrooms and moving out into the community on carefully prepared trips to stores, cafeterias, etc.. So far, three children have moved full-time into normal classes, and five are integrated part-time.

Not every child will move toward communication in the same way; for one it may be through music, for another through swimming. The initial area of communication is then expanded step by step in a highly structured program.

Dr. Giraldi considers that autism represents "the ultimate in severity of the communicative disorders," and that this "ultimate challenge in communication" holds the key to these disorders in man. He anticipates that work with autistic children will lead to much more rapid diagnosis and treatment of emotional problems, with "a form of instant analysis" as an ultimate goal. In the meantime, in Mrs. Koehler's classroom, autistic children are enjoying their right to a public education.

**Mrs. Koehler is a teacher with many years of experience with the educable retarded. Her pioneering work has attracted much community recognition and support.**

**Dr. Giraldi, a Captain in the Marine Corps, is now setting up a laboratory for the study of the communicative disorders in children at Letterman General Hospital. The full text of his paper quoted above, "The Multi-Stimuli Approach in the Treatment of the Autistic Child May Lead to Instant Analysis," is available from NSAC on request.**

# THE IRISH SOCIETY FOR AUTISTIC CHILDREN

Dr. Catherine Crawley
Lecturer in Neuro-Anatomy, University College, Dublin

Dr. Crawley described the development of the Irish Society for Autistic Children from its birth in November, 1963, "out of the frustrations, fears, and heartbreak of seven sets of parents." The campaign to bring autism to the attention of a previously unaware public had a particular advantage: "in our country which is deeply and abidingly religious there was immediate sympathy for this unusual child because he was 'A duine le Dia,' a Child of God." The Society received letters daily from people who were trying to cope with childhood problems they could not understand and who received little help from doctors who, however sympathetic, were perplexed themselves. No facilities existed for care and treatment.

Largely as a result of the Society's activity, both residential and day-care facilities are now available in the Dublin area. By the end of 1970 there will be 130 autistic or severely emotionally disturbed children being cared for in Dublin City, although even with the expansion of facilities there are still waiting lists. There are as yet no Regional Centers, although children in all parts of the country, including Northern Ireland, are seen by a representative of the Society. The Society distributes informational materials, including its own booklet, and is in close contact with the Irish Department of Health.

The skills needed for dealing with "children apart" are not notably enhanced by expensive training. In Dr. Crowley's words: "Far be it from me to advocate charlatan services, but good work has been done before by dedicated people without involving the expenditure of enormous sums of money. Any service would be appreciated by the many parents throughout Ireland who are distracted and frustrated -- to them half a loaf is better than no bread. The Society has asked that as an interim measure there be attached to every center for the mentally handicapped throughout the country a special room reserved for the care and training of autistic and severely disturbed children. Not only are these children at risk -- their siblings are at risk, as are the parents themselves. Unless something is done, and done soon, these unfortunate children will be sent to the adult wards of mental hospitals where they will vegetate for the rest of their lives at enormous cost to the state." For those children now receiving treatment, sheltered workshops must be provided where they can spend their adult lives usefully in gainful employment. Unless this is done, all the money, both public and private, and all the specialized skill expended on their training will have been in vain.

It is expected that 50% of the children now under care will have progressed sufficiently to adapt to sheltered employment. A few have been discharged to normal schools. Complete recovery is rare.

"It has been alleged that autism is a disease of the children of parents in higher income and intellectual brackets. This, I do not believe. I was largely responsible for the provision of a diagnostic unit in the center of a slum area where all facilities were free. Immediately the little patients began to appear in appreciable numbers."

"In the context of conditions in my country, regional centers with as many children on day-care as possible seems to be the best answer. No matter how good the center or how dedicated the staff or how excellent the therapists, I believe that nothing can ever compensate a child for the love and care which he receives as a natural right in his own family. It is also better for the parents, who do not have as their daily companion the enormous and soul-destroying load of guilt (sometimes, unfortunately, iatrogenically induced) which seems to follow inevitably on the parting from these very lovable children."

**Dr. Crawley, Founder of the Irish Society, is the mother of a 16-year old autistic boy. A specialist in neuroanatomy and embryology, she is at present engaged in research into the causes of autism.**

# HELP YOUR COMMUNITY HELP YOUR HANDICAPPED CHILD

Herman S. Preiser
Coordinator, Child Studies Program
Antioch-Columbia, Md.

"Five years ago, my wife and I were on the edge of desperation and exhaustion. Our autistic son was nearing his sixth birthday and we could not find a suitable school for him in our county or anywhere else. We had been endlessly referred to doctors, psychologists, hospitals and special clinics for countless hours of counseling, examinations, so-called therapy, diagnoses and other soul-searching treatments. No doctor would prescribe drugs for our son's hyperactivity. No psychologist or social worker would offer any hope for our son's improvement or recovery. No educator would attempt to teach him rudimentary skills. Neighbors, friends and family turned away from us in apathy or disgust. Everyone recommended institutionalization for our son. We were alone and afraid."

"Today, after almost herculean efforts on the part of a few highly motivated people, Howard County, Maryland, is taking the lead in providing a whole range of diagnostic and prescriptive services in areas of medicine, education, recreation, vocational training, and social adjustment. Many stages of these programs are fully operational, while others are in various stages of implementation and demonstration. The long-term view is encouraging and challenging. My son attends a private day school in the community, the total cost being borne by the county and state. He participates in a physical development clinic and a swim club on weekends. Most important, he is being accepted as a young citizen in his community making courageous efforts to reach self-fulfillment."

Mr. Preiser's paper, copies of which are available from NSAC, presents a detailed account of "how this came about and how you can replicate, expand, and improve it." He describes the passage of enabling legislation at the state level, the allocation of county funds for private schools, and the establishment of a Child Study Center. This center, which provides classes for handicapped children unable to obtain places in existing school programs, is shifting its emphasis to helping the schools to receive them. It provides supportive services to teachers and educational diagnosis and prescription of programs by means of resource teams that work with children and teachers in their home schools. Para-educational services of the Center medical and psychological personnel are available as needed. A county Association for Special Education unites all parents of the handicapped on a PTA model and has an active Teen-Auxiliary and Community Center. A demonstration summer recreation program is described. The new Antioch-Columbia Child Study Program is discussed, as well as the work of Dr. Warren Johnson's Children's Physical Development Clinic at the University of Maryland. The situation in 1965 -- when the public school system had special classes only for the mentally retarded, and handicapped children not fitting into these classes were excluded -- has rapidly changed, "as a result of continual parent pressures leading to legislative action at the state level and program implementation at the local level."

**Mr. Preiser, a corrosion engineer, is on sabbatical leave to devote his full time to aiding handicapped children. He is serving as community coordinator to establish a Child Studies Institute at Antioch College, Columbia, Md., and Administrative Editor of the forthcoming Journal of Autism and Childhood Schizophrenia.**

## LIST OF FILMS

"The Chemistry of Behavior" -- a study of the effect of psycho-active drugs on behavior.
Audio-Visual Center, University of Indiana, Bloomington, Indiana 47401.

"Far From the World" -- the evolution of an autistic boy filmed by Dr. Alfred Brauner of Paris.

"Aids for Teaching the Mentally Retarded" -- a gold mine of special education techniques in a series of five short films. Motor, perceptual, social skills and sheltered workshop featured.
Thorne Films, 1229 University Avenue, Boulder, Colorado

"Developmental Progress of a Psychotic Child" -- one autistic child in Dr. Eric Schopler's program over a two-year period.
Contact: Mrs. Lynn Dick (966-4270) Dept. of Psychiatry, School of Medicine, University of North Carolina, Chapel Hill, N.C. 27514.
Special rate of $10.00 to NSAC chapters.

"The Hyperactive Child" -- a close look at children with some of the symptoms we see in our own children.
CIBA Pharmaceuticals, Summit, New Jersey 07901.

"Comedian, I.Q. 50" -- another by Dr. Brauner, depicting a spontaneous and dramatic expression of mentally retarded and psychotic children; it touches on adolescence.

"Lost Ones, Loved Ones" -- filmed by Bob Allers, narrated by Paul Newman. Reinforcement therapy with mentally ill children.

"Autism--The Invisible Wall" -- the University of Oklahoma film features the Sullivan family and other NSAC notables under the direction of Dr. Barnett Addis.
Available from NSAC for postage as is also "The Foal" -- the episode about an autistic boy in the "Marcus Welby" series.
Contact: Mrs. Duncan Williams, 951 Main St., Barboursville, West Virginia 25504.

For other films, we suggest you get a catalogue from your own state university center for audio-visual instruction.

# CITATIONS AND AWARDS

presented at
THE ANNUAL MEETING OF THE NATIONAL SOCIETY FOR AUTISTIC CHILDREN

## CITATION

The National Society for Autistic Children
honors
Mary Stewart Goodwin, M.D.
and
T. Campbell Goodwin M.D.

for distinguished service to mentally ill children and their families, and for their kindness and devotion far beyond the call of duty.

June, 1970

## CITATION

The National Society for Autistic Children
honors
Carl Fenichel, Ed.D.

distinguished pioneer educator of mentally ill children, and dedicated friend and counsellor to their parents.

June, 1970

## CITATION

The National Society for Autistic Children
honors
Ruth Christ Sullivan
its esteemed president July, 1968 to June, 1970

for her selfless dedication and tireless, imaginative efforts on behalf of our children.

June, 1970

## PUBLIC SERVICE AWARD

The National Society for Autistic Children
honors
David J. O'Connell

for his film, "The Foal", an authentic and compelling story of an autistic child and his family.

June, 1970

## AWARD

The National Society for Autistic Children
honors
Robert Young

for his help in bringing national attention to the desperate needs of autistic children and their families.

June, 1970

END